



THE CLINIC-BASED SURVEILLANCE- INFORMED (CBSI) INTERVENTION



Center for
Innovation and
Engagement

Background

The Health Resources and Services Administration's (HRSA's) Ryan White HIV/AIDS Program (RWHAP) provides a comprehensive system of HIV primary medical care, essential support services, and medications for low-income people living with HIV who are uninsured and underserved. RWHAP funds states, cities, counties, and local community-based organizations to provide care and treatment services to people with HIV to improve health outcomes and reduce HIV transmission among hard-to-reach populations.

NASTAD's Center for Innovation and Engagement (CIE) is funded by HRSA's HIV/AIDS Bureau (HAB), RWHAP Part F, Special Projects of National Significance (SPNS), under a three-year cooperative agreement entitled Evidence-Informed Approaches to Improving Health Outcomes for People with HIV. The purpose of this initiative is to identify, catalog, disseminate, and support the replication of evidence-informed approaches and interventions to engage people with HIV who are not receiving HIV health care or who are at risk of not continuing to receive HIV health care.

Acknowledgements

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Intervention Snapshot

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|  | <p>Priority Population</p> | <p>People with HIV who are not in care</p> |
|  | <p>Setting</p> | <p>Ryan White HIV/AIDS Program Clinic</p> |
|  | <p>Pilot and Trial Sites</p> | <p>Madison Clinic at Harborview Medical Center in Seattle, Washington, in collaboration with Public Health-Seattle & King County</p> |
|  | <p>Model</p> | <p>The CBSI intervention uses clinical data to create a list of clients who appear to be out of care for at least one year and matches the list with HIV surveillance data to inform follow-up by the clinic. Staff investigate each eligible case, systematically attempt to contact each client, and assist clients with scheduling and completing medical visits. Upon re-engagement, staff support clients to stay engaged in care by continuing to address health and social needs such as referral to support services, connection to ancillary services, counseling, health systems navigation, and transportation.</p> |
|  | <p>RWHAP Ending the Epidemic (EHE) Opportunity</p> | <p>People with HIV who receive ongoing, regularly scheduled care are more likely to have significantly lower viral loads, higher CD4 cell counts, reduced morbidity and mortality, and improved overall health than those who missed even one medical visit over a two-year period. Intervention outcomes indicate the feasibility of combining clinic and HIV surveillance data to identify clients who may be out of care and improve linkage and retention in care. The intervention further indicated significant improvements in viral suppression outcomes as the time to relinkage was shorter among clients in the intervention cohort and a greater proportion were relinked to care (15 percent vs. 10 percent in the adapted model).</p> |
|  | <p>Intervention Funding</p> | <p>The intervention was funded and evaluated under a RWHAP Part A grant.</p> |
|  | <p>Staffing</p> | <p>Staff positions in the original intervention included a Data Manager and Linkage Specialist.</p> |
|  | <p>Infrastructure Needed</p> | <p>Electronic health records or an electronic medical record database to store and track the gathered information Data systems to extract client data from electronic health records and facilitate data sharing between health departments and providers while adhering to necessary data privacy regulations</p> |



Intervention Overview & Replication Tips

Why This Intervention?

The Clinic-Based Surveillance-Informed (CBSI) intervention is a clinic-based program implemented in a large HIV clinic in Washington State in a collaboration between the clinic and the local health department. The intervention used clinic data to create a list of clients who appeared to have been out of care and matched the list with HIV surveillance data to inform the clinic's outreach. Clients were considered out of care and eligible for the clinic relinkage intervention if they: (1) were living with HIV; (2) had not died or transferred care; (3) had completed at least one visit in the past 1,000 days; and (4) had not completed a visit for at least 12 months prior to the date on which their record was extracted.

The CBSI intervention demonstrated the feasibility of combining clinic and HIV surveillance data to identify clients who may be out of care and improve linkage and retention in care for people with HIV. A total of 753 patients were identified as out of care on November 1, 2012. Matching with surveillance data and initial investigations found 596 (79 percent) of these patients had moved,

transferred care, or were incarcerated. Of the 157 remaining patients, 40 (25 percent) relinked to care before contact, and the linkage specialist successfully contacted 38 (24 percent).

The intervention further showed that a clinic-based relinkage program conducted in collaboration with a local health department could significantly decrease re-engagement time for clients in HIV care and increase the likelihood that clients will relink to care. Compared with a historical control group, the time to relinkage was shorter among clients in the intervention cohort (adjusted hazard ratio = 1.7 [1.2–2.3]), and a greater proportion of clients in this cohort relinked to care (15 percent vs. 10 percent).¹ Although the study showed modest effectiveness in relinking clients to care, these outcomes underscore the importance of leveraging clinic and public health data to improve data accuracy and precision, thereby enhancing relinkage activities.

The CBSI intervention is intended for use in clinics and private provider practices.

“[Before] surveillance [we] hit three sentinel events: your HIV diagnosis, your AIDS diagnosis, and your death. You really didn’t go back to the record in between. Having these other opportunities to go back and list matches against other facilities has become really helpful. We’re breaking those walls down now, and we’re saying that really, it is in the best interest of the patient to communicate this information back.”

– PUBLIC HEALTH-SEATTLE & KING COUNTY EPIDEMIOLOGIST

Intervention at a Glance

This section provides a breakdown of the CBSI intervention conducted at the Madison Clinic at Harborview Medical Center in Seattle, Washington, in collaboration with Public Health-Seattle & King County (PHSKC), to help readers assess the steps required for replication. The intervention was funded and evaluated under the Health Resources and Services Administration (HRSA) Ryan White HIV/AIDS Program (RWHAP) Part A grant.

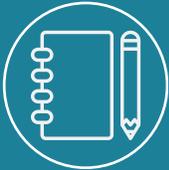
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|---|---|
|  <p>Step 1</p> | <p>Assess Staff Resources and Gaps:</p> <p>Ensure that your staff—HIV outreach workers, linkage specialists, surveillance staff—possess the skills needed to conduct a systematic review of electronic health records (EHR), manage data sharing between the health department and the clinic, locate people with HIV who are out of care, and offer assistance with linkage to needed services.</p> |
|  <p>Step 2</p> | <p>Explore Existing or New Data Infrastructure:</p> <p>Use a data system (e.g., an EHR system) to store and track the gathered information.</p> |
|  <p>Step 3</p> | <p>Engage Stakeholders:</p> <p>Meet with health department and medical staff to discuss conducting the intervention, develop data-sharing agreements, and obtain community input to increase the likelihood of developing and implementing a successful program acceptable to all parties involved.</p> |



Step 4

Generate a Local “Out-of-Care” Definition:

A local definition is how your organization identifies people out of care. An example is “No evidence of CD4 counts, viral load results, an HIV medical care visit, and/or a prescription for antiretroviral therapy (ART) within a 15-month period.”



Step 5

Create a Client List:

Use the data system to make a list of clients who are out of care according to your local definition.



Step 6

Decide on Data-Sharing Methods:

Determine how to securely transfer client lists to the health department for data matching (e.g., use a safe data file transfer program; have conversations as needed about the frequency of data extraction and data-matching).



Step 7

Prioritize Client List:

Determine the size of the population that appears to need relinkage. Prioritize the list based on capacity and other factors, such as the number of staff available to locate clients and assist them with returning to and staying engaged in HIV medical care. Further prioritize your list based on priority populations, geographic location, and other locally relevant factors, such as clients who were viremic at their last medical visit.



Step 8

Designate Linkage Specialists:

Use your prioritized client list to determine the number of linkage specialists needed to implement the relinkage intervention.



Step 9

Establish a Communication Protocol:

Develop processes for contacting clients (e.g., phone calls, emails, texts, field visits) and outline steps to relink them based on their health and social needs.



Step 10

Relink and Retain Clients:

After making initial contact with clients, assess the factors associated with re-engagement and connect them to appropriate staff and services. Support clients with staying engaged in care by linking them to support services that address retention and adherence barriers.

Cost Analysis

The cost analysis was developed based on the economic peer-reviewed literature on best practices for Budget Impact Analysis (BIA) and Cost-Effectiveness Analysis (CEA).^{2,3} To ensure standardization and translation across other cost analyses of HIV-related interventions, data collection tools were further informed by tools used in a previous cost analysis of HIV linkage and retention in care interventions, cost analysis study descriptions included in this project's original notice of award (funding opportunity announcement number HRSA-15-030), as well as feedback from HIV intervention developers and cost analysis experts collaborating with the Center for Innovation and Engagement (CIE) project.⁴

The following estimates are summarized from data gathered on different components of this intervention, including the costs of personnel, fringe benefits, supervision and training, clinical support services, number of people served, types of visits that can be linked to costs/patient outcomes, and other direct and indirect costs. For a complete description of the intervention cost data based on the implementation described in this manual, please refer to the link in the [Additional Resources Box](#).

The CBSI intervention was sustained by a HRSA RWHAP Part A grant. The federal program supports direct care and treatment services, and Part A is used to provide core medical and support services for people with HIV. Support services that enhance HIV care for people with HIV can also be funded through this category. HRSA's Ryan White HIV/AIDS Program Fact Sheet provides more context on the different parts. Additionally, RWHAP's Policy Clarification Notice 16-02 outlines details on allowable costs. ([See Additional Resources Box](#)).

When the intervention was implemented, the estimated annual direct program cost was \$78,760 and \$122,078 including the 55 percent indirect rate expense of the intervention developer (Table 1). Staffing and personnel costs accounted for 97 percent of all direct costs. This included a part-time data manager, a health department Disease Intervention Specialist (DIS), a linkage to care specialist, and a medical director. Non-personnel costs accounted for 3 percent of direct program costs and included staff computer-related expenses and travel. There were no client-specific costs involved.

The Linkage Specialist (LS) conducted 406 case investigations of people potentially out of care, and attempted contacting 117 individuals. Out of the 406 individuals, 38 (9.3 percent) were contacted and enrolled over a 12-month period. At maximum capacity, intervention developers estimated they could enroll up to 60 clients a year.



\$122,078

total cost of the
intervention
per year



10

clients served
per project
personnel



9.4

percent of clients
served among all
attempted contacts

Table 1 — Clients Served, Program Costs and Costs per Client

| Cost Analysis Results | | |
|--|--------------------------------------|---|
| Clients Served | | |
| Percent of Clients Served Among All Attempted Contacts | 9.4 percent | |
| Clients Served Per Project Personnel (full-time and part-time) | 10 | |
| Annual Program Cost | Including Indirect/ Overhead Rate | Direct Costs (Excluding Indirect Rate) |
| Total Cost of the Intervention Per Year | \$122,078 | \$78,760 |
| Annual Personnel Costs | \$118,203 | \$76,260 |
| Percent of Total Costs | 96.8 percent | 96.8 percent |
| Annual Costs for Materials/Supplies/Equipment | \$3,875 | \$2,500 |
| Percent of Total Costs | 3.2 percent | 3.2 percent |
| Annual Client-Specific Costs | \$0 | \$0 |
| Percent of Total Costs | 0 percent | 0 percent |
| Cost Per Client | | |
| Cost Per Client Served | \$3,213 | \$2,073 |
| Personnel Cost Per Client Served | \$3,111 | \$2,007 |
| Cost Per Maximum Clients | \$2,035 | \$1,313 |
| Personnel Cost Per Maximum Number of Clients | \$1,970 | \$1,271 |

The direct cost per client served was \$2,073 and \$1,313 per client at maximum capacity (Table 1). Considering only personnel implementation costs, the cost per client served was \$2,007 and \$1,271 per client at maximum capacity. A total of 9.5 clients were served per intervention personnel and 34.9 per intervention full-time equivalent employees (FTE).

Organizations interested in estimating the cost of implementing this intervention in their jurisdiction are encouraged to utilize the CIE Cost Calculator Tool. ([See Additional Resources Box](#)).

Resource Assessment Checklist

Before implementing the CBSI intervention, your organization should walk through the following Resource Assessment (or Readiness) Checklist to assess your ability to do this work. If you do not have these components in place, you are encouraged to develop this capacity to conduct this intervention successfully. Questions to consider include the following:

- Does your staff understand HIV trends in your community and interconnected social determinants of health that impact health outcomes?
- Are staff within your organization willing to work with you on planning and implementing this intervention?
- Does your organization have HIV outreach workers, linkage specialists, medical case managers, or other staff who can locate and relink clients to care? If not, are you able to obtain the necessary staff either directly or through partnerships?
- Does your organization have:
 - At least one staff person with sufficient training to use your clinic's data system (e.g., navigating through client-level information, extracting and synthesizing data)? If so, does this staff member have the flexibility to work with and re-engage a client who is out of care (e.g., quickly make an appointment)?
 - An EHR system or electronic medical record database from which to extract information about clients who are out of care and in which to store this information securely?
- Data systems in place, or the resources necessary, to extract client data from the EHR and send it to the health department for matching with HIV surveillance data?
- A standard system for documenting clients' HIV outcomes?
- Can your organizational structure provide both medical services and linkages to ancillary services (e.g., housing, transportation, legal, or mental health services)?
- Does your organization have an existing relationship with the local health department, or is the health department willing to begin a conversation about data sharing for linkage to and retention in HIV care?
- Does your jurisdiction have statutes in place that allow health departments to share clients' care status with providers?
- Does your organization have funding sources (e.g., Ryan White HIV/AIDS Program [RWHAP] Part C funding) to support clinic-based and surveillance-informed activities?

Setting the Stage

According to the U.S. Centers for Disease Control and Prevention (CDC), there is an estimated 1.2 million people with HIV in the United States.⁵ During 2018, approximately 75.7 percent of people with HIV received HIV medical care, 57.9 percent were retained in care, and 64.7 percent were virally suppressed.⁶ People with HIV who receive ongoing, regularly scheduled care are more likely to have significantly lower viral loads, higher CD4 cell counts, reduced morbidity and mortality, and improved overall health than those who missed even one medical visit over a two-year period.⁷ Receipt of medical care is defined as a client taking one or more tests [CD4 or viral load] in the measurement year. Although significant strides have been made in ensuring that people with HIV effectively progress through the HIV care continuum, these figures demonstrate that retention continues to be a critical issue. Improving client engagement and re-engagement in care is a national priority with targeted retention measures established by the HIV National Strategic Plan ([see Additional Resources Box](#)), HRSA, and the Ending the HIV Epidemic (EHE) initiative, among others.

The Madison Clinic is the largest HIV specialty clinic in the northwestern United States, providing care to approximately 2,800 people. In 2012, when the Madison Clinic conducted the CBSI intervention, 7,104 King County residents were documented as having HIV.⁸ At that time, most residents with HIV were men (89 percent), men who have sex with men (69 percent), between ages 25 and 39 years (59 percent), and U.S.-born and white (62 percent). People with HIV who are U.S.-born and Black were and continue to be a relatively small part of the HIV epidemic in King County. However, among foreign-born people with HIV in King County, 39 percent were Black, and 34 percent were Hispanic in 2012. Among all people diagnosed with HIV in King County, 75 percent had some laboratory evidence of medical care.⁸ The CBSI intervention allowed the clinic to link people with HIV to care, taking into consideration these epidemiological trends.

In 2010, before implementing the intervention, the developers conducted a mix of qualitative interviews with clients, staff, and providers. This series of interviews included 20 people with HIV who were randomly selected from HIV



surveillance records. Some providers were eager to get clients back into the clinic and to develop a routine way to identify those who were falling out of care. Other providers were concerned about information security and client perceptions of surveillance systems. Conversely, clients almost uniformly considered the intervention to be promising. More specifically, clients expressed an interest in receiving more linkage assistance, such as consistent follow-up and being connected to comprehensive services and quality care.⁹

Epidemiological trends and findings from qualitative interviews with clients and providers indicated a need for the CBSI intervention in the Seattle-King County area. Findings from the qualitative interviews led the Madison Clinic to design the CBSI intervention to incorporate an HIV-positive peer component and to ensure coordination with HIV care providers in relinking clients to care. Although the intervention is not currently sustained as originally designed, it continues to be integral to linkage and retention efforts both at the Madison Clinic and in King County. By scaling up surveillance activities and conducting comprehensive investigations of people identified as out of care, the intervention successfully relinked people to care and addressed the needs of populations that have been historically marginalized and have limited access to resources. Over time, intervention developers adapted the CBSI intervention to create the Moderate assistance (Mod) and Maximum assistance (Max) clinics, which provide differentiated models of care for clients depending on the level of support needed to re-engage and stay in care.

Description of the Intervention Model

The CBSI intervention aims to link people to a system of HIV medical care in which they can stay engaged and to improve the accuracy of the client engagement data available to clinics. The intervention aims to successfully re-engage and retain people with HIV who have not been linked to or engaged in HIV medical care.

The keys to success are to investigate each eligible case, systematically attempt to contact each client, and assist clients with scheduling and completing medical visits. This work can be done in coordination with case managers and medical providers. Upon re-engagement, staff can support clients to stay engaged in care by continuing to address health and social needs (e.g., referral to support services, connection to ancillary services, counseling, health systems navigation, transportation).

The CBSI intervention is implemented in five steps:

1. Determine Organizational Resources and Engage Stakeholders

- a. *Assess Staff Resources and Gaps:* Identify staff who currently work as linkage specialists, HIV outreach workers, or in other similar roles. Also, identify staff who can navigate the EHR system and manage databases containing client-level data. Decide if existing staff can be cross-trained to fulfill these roles or if additional staff are needed. Having at least one staff person who is dedicated to the intervention is key to ensuring its success.
- b. *Explore Existing or New Data Infrastructure:* A data system, such as an EHR system, is necessary to identify clients who are out of care and extract relevant information about them. The data system should allow designated staff to extract a list of clients who are out of care to provide to the health department's HIV Surveillance Program. Data in this list should match entries on the Enhanced HIV/AIDS Reporting System (eHARS), a browser-based, CDC-developed application that assists health departments with reporting, data management, analysis, and transfer of data to the CDC.¹⁰

- c. *Engage Stakeholders:* Meet with the local or state health department to discuss conducting the intervention, identify potential security issues, develop a data-sharing agreement, create a data-sharing protocol, determine a data-transfer method, and identify data to be included in the list of out-of-care clients as well as formatting requirements for the list. During initial conversations with health departments, you should inquire about statute(s) that prevent or facilitate data sharing between health departments and providers.

It is also crucial to integrate clients' perspectives into these processes. Before beginning linkage and retention activities, staff should brainstorm ways to meaningfully engage people with HIV and discuss the intervention with them. Gather community input through activities such as focus groups, one-on-one conversations, and meetings with community advisory boards.

“Surveillance work has been traditionally siloed, kept in a separate locked database, and separate locked room, with limited access to it. People who are out of care may also be exposed to other STDs such as gonorrhea and chlamydia. They may be hitting the system in many different ways. If these systems can't talk to each other, it's a big, huge barrier.”

— PUBLIC HEALTH-SEATTLE & KING COUNTY
EPIDEMIOLOGIST

2. Identify Eligible Clients

a. *Generate a Local Out-of-Care Definition:*

To develop a relevant and actionable list of people with HIV who are out of care, you should first develop a local definition of *out of care*. Consider modifying the definition used at the Madison Clinic: Clients are considered to be out of care and eligible for the relinkage intervention if they (1) are living with HIV; (2) have not died or transferred care; (3) completed at least one visit in the past 1,000 days; and (4) have not completed a visit for at least 12 months prior to the extraction date. While definitions of out of care are based on national HIV care quality measures developed by agencies such as the CDC, there are opportunities to adapt them to reflect the local context.

Suggested modifications of this definition include:

- Extending the time since the last visit from at least 12 months to at least 15 months to

exclude clients who are in care but come in only every 13 to 14 months,

- Focusing on viral suppression at the last medical visit rather than on the absence of recent lab results, and
 - Adding three or more no-shows in the last year to the list of criteria.
- b. *Create a Client List:* Search the data system for clients who meet the local out-of-care definition criteria. Create the list by performing queries on the EHR system or analyzing client-level information from a database used at the care site. Extract the list of clients who are out of care and ensure that the data are organized in an accessible format. Clients referred to the linkage specialist may also be included on this list. Exclude clients for whom evidence shows that they have moved, engaged in care elsewhere, relinked themselves to care, or self-reported being back in care when staff contacted them. This will facilitate generating an accurate list of out-of-care clients and, later, evaluate the intervention's true impact.

“There were a number of other ways that people would find their way onto my workload. I would take referrals from providers, social workers, and patient care coordinators who conducted intakes with clients. Sometimes, these were clients who were newly referred to care who then never showed up for their first appointment. I also got a list of people who were in-patient at Harborview Hospital with HIV or who had a positive HIV test. I would take a quick look through that list every day and see if there was anybody who was a patient at our clinic and hadn’t been in, in a while.”

– MADISON CLINIC OUTREACH WORKER

3. Share Data with the Health Department for Matching with HIV Surveillance Registry

- a. *Create Data Use Agreement:* Before sharing data, it may be necessary to establish a data use agreement between the health department and the organization. The data shared are considered protected health information (PHI) and can thus be bound by HIPPA privacy rules. Discuss the protocol that the organization will need to follow to access and use data.
- b. *Securely Share Data:* Establish a preferred method for securely transmitting client-level data between your organization and the health department. Examples of secure methods include a secure file transfer protocol (SFTP) or other web-based disease surveillance or case management system that facilitates data sharing and coordination. Once a data-sharing mechanism is in place, your clinic sends the list of clients who meet the local out-of-care criteria to the local or state health department. The health department then matches the list with its HIV surveillance data, using eHARS or another database that stores HIV surveillance data. The health department identifies clients who have transferred to HIV care elsewhere, have moved away, are deceased, or are incarcerated, and designates these cases as “outreach not indicated.” The linkage specialist is not required to investigate these cases or attempt further outreach. This data-sharing process is beneficial for both your clinic and the health department.

Jurisdictional statutes dictate whether laboratories must report CD4 and viral load results to the health department. Laboratory reports may include the names of medical providers or medical practices ordering laboratory tests and can be used to identify clients who may have transferred their care to other clinics. Surveillance staff match HIV case records with death records annually. Some health departments individually investigate

“The key is to get just more than those matching elements. You want more than name, date of birth, and sex assigned at birth. As a surveillance program, you want more data. For example, the date the client was last seen in your clinic, current gender, their exposure risk—health departments are filling out their surveillance data at the same time.”

– PUBLIC HEALTH-SEATTLE & KING COUNTY
EPIDEMIOLOGIST

all cases for which no CD4 or viral loads have been reported for a selected period of time (e.g., within one measurement year when using the CDC out-of-care definition).

After the first list of out-of-care clients has been matched with health department surveillance data, the frequency at which lists will be created and matched with health department data will be determined. The frequency may be:

- Clinic-driven (i.e., the clinic determines how frequently it will request updated lists from the health department),
- Based on staff capacity, or
- Determined during initial conversations with the health department or after clinic staff begins investigating the initial list of out-of-care clients.

4. Review the List Received from the Health Department

- a. *Prioritize the Client List:* Before reaching out to clients, explore how to prioritize your client list systematically. For example, you may prioritize the list by determining how many full-time equivalents (FTEs) are needed to re-engage a certain number of people with HIV into care. (One FTE is defined as the number of hours worked by one full-time employee. Two half-time employees are equivalent to one FTE).

Alternatively, you may prioritize the list based on organizational priorities or local criteria (e.g., by selecting clients who were not virally suppressed at their last visit, focusing on priority populations, or clients in a particular ZIP code). For example, if one of your goals is to improve viral suppression for Black clients, consider prioritizing outreach to these communities and making a concerted effort to re-engage them in care. It is helpful to have a dedicated and practical client list to increase the efficiency and effectiveness of linkage-to-care efforts.

The *Prioritizing an Out of HIV Medical Care List* tool offers a method of prioritizing the list of clients who are out of care and determining the level of staff effort required to re-engage them. ([See Additional Resources Box](#)).

5. Re-engage Clients in Care

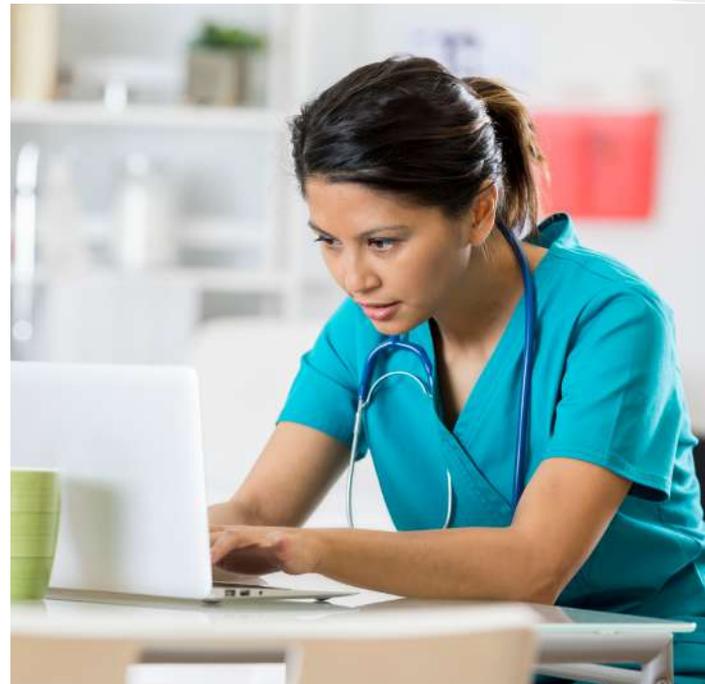
- a. *Designate Linkage Specialists:* Use the size of the population that appears to need relinkage assistance to determine the number of linkage specialists needed to implement the intervention. Before hiring new staff, ask current staff to determine the amount of time required for intervention activities and the success rate of these activities.
- b. *Establish a Communication Protocol:* Before beginning outreach efforts, outline concrete steps for contacting clients. Depending on clinic policies, communication methods may include phone calls, text messages, emails, and corresponding with external providers or organizations. The protocol used by interventionists at the Madison Clinic includes the following steps, in priority order:
 1. Three attempts at phone contact using the phone numbers on record,
 2. One attempt by email if an email address is available,
 3. One attempt to contact outside agencies for which a *Release of Information Form* is on file in the medical or case management records, and
 4. One attempt to call the designated emergency contact.

“I would also look and see if clients had any active ‘Releases of Information’ for other service agencies or anything with their social worker. I talked with nurses and social workers, and I visited clients who showed up in-patient if they got admitted into the hospital. We introduce ourselves, try to get to know them a little bit, and remind them that we would really like them to come into the clinic, that we cared about them, and that we wanted to make that as easy as possible.”

– MADISON CLINIC OUTREACH WORKER

If the linkage specialist communicates with someone other than the client (e.g., a family member, friend), they should state their name and request assistance in contacting the client. The linkage specialist does not discuss the reason for the call or identify either the clinic or the hospital, or other organization in which the clinic is located.

- c. *Relink and Retain Clients:* To inform successful service delivery, first develop working definitions for relinkage and retention, and then create and execute a plan to relink clients to care. The Madison clinic defined *relinkage* as the completion of at least one visit within 12 months and *retention* as the completion of two or more visits that are three or more months apart. This care measure is consistent with HRSA/HAB HIV performance measures. The Madison Clinic used retention as an outcome measure for evaluating the original intervention. However, the linkage specialist did not use retention as a measure to assess their activities during the implementation of the intervention.
- d. *Steps in a Relinkage Plan:*
 1. *Inquire About the Client's Absence from Care and Gauge Their Interest in Re-engagement:* When a linkage specialist contacts a client, they should state their name, affiliation, and reason for the call. The linkage specialist then asks whether the client has indeed been absent from HIV medical care for a year or more. If the client has been out of care, the linkage specialist states their interest in helping the client relink to care.
 2. *Connect with Appropriate Clinical Staff to Schedule Follow-Up Appointments for Clients:* The linkage specialist works with the client, their case manager, medical provider, and clinic triage and clerical



staff to schedule a follow-up appointment. Because the linkage specialist serves as the direct link between the client and providers, it is helpful for them to contact the providers directly to schedule client appointments. Providers may then prioritize the linkage specialist's clients and be willing to overbook to fit them in or give them a slot that had been blocked off. Throughout this process, it can also be helpful for the linkage specialist to be in contact with disease intervention specialists (DIS) at the health department to provide relevant updates and address barriers to scheduling follow-up appointments for clients.

3. *Conduct Appointment Reminders and Follow-Up:* The linkage specialist reminds clients of appointments as needed and follows up with clients to confirm that they have attended their appointments.

Logic Model

Logic models are effective tools to assist in planning, implementing, and managing an intervention. Below is a logic model highlighting the resources, activities, outputs, outcomes, and impact of the Clinic-Based Surveillance-Informed intervention referenced throughout this guide.

| Resources | Activities | Outputs | Outcomes | Impact |
|---|---|---|---|---|
| <ul style="list-style-type: none"> • RWHAP or a funding source that supports surveillance activities • Linkage specialist and data manager • Relationships and collaborations with local or state health departments, medical staff, and client population • Data system (e.g., EHR system) | <ul style="list-style-type: none"> • Engage stakeholders and obtain community input • Search data system and identify clients who are out of care • Securely transfer data to health department • Match data • Prioritize client list • Conduct client outreach • Schedule client appointments • Follow-up with client after appointment completion | <ul style="list-style-type: none"> • Data-sharing process • Better understanding of the true out-of-care population • Relinkage and retention of people with HIV who have been out of care | <p>Among people with HIV:</p> <ul style="list-style-type: none"> • Relinkage to services that meet their health and social needs • Decreased time to HIV care re-engagement • Improvement in HIV and overall health outcomes <p>Within the organization implementing the intervention:</p> <ul style="list-style-type: none"> • Enhanced relinkage activities • Enhanced infrastructure to inform outreach to people with HIV • Demonstrated investment in the client population and HIV relinkage efforts • Strengthened relationships with health department(s) and community stakeholders | <ul style="list-style-type: none"> • Reduced HIV morbidity and mortality • Reduced HIV transmission • Advanced health equity for people with HIV |

Your Planned Work

Your Intended Results

Staffing Requirements & Considerations

Staff Capacity

The following staff implemented the CBSI intervention at the Madison Clinic:

- *Data Manager:* The data manager's responsibilities include:
 - Identifying clients in the clinic EHR system who meet the local out-of-care definition;
 - Consolidating and coordinating the transfer of client data to public health HIV surveillance epidemiologists for data matching; and
 - Sharing the updated list of out-of-care clients that is received from the health department with the linkage specialist.
- *Linkage Specialist:* The linkage specialist investigates each eligible case, attempts to contact clients, and assists clients with scheduling and completing medical visits. The linkage specialist also works across teams with case managers, medical providers, and clinic triage and clerical staff to relink and retain clients who are out of care. The linkage specialist's responsibilities include:
 - Searching the EHR for information about each client's status and attempting to contact each client;
 - Scheduling a follow-up appointment, reminding clients of appointments as needed, and following up to determine whether the relinkage appointment was completed; and
 - Following clients, until they have completed an appointment, declined to return to the clinic for care, or are referred to the health department for further outreach by DIS and other outreach workers. The linkage specialist's contact with clients may be primarily by phone. When needed, the linkage specialist may offer to meet clients outside of the clinic, assist with transportation, or, in the case of hospitalized clients, visit clients in the in-patient unit. The linkage specialist also attends training sessions and periodic meetings related to HIV care engagement and ART use.

Staff Characteristics

Core competencies of all staff should include:

- A personable demeanor and flexibility in identifying individual client needs;
- Ability to systematically apply definitions, track data, and conduct investigations;
- Experience with client navigation or prior work at community-based HIV organizations;
- Familiarity with the clinic and its dynamics;
- Fluency in Spanish and English (or other languages based on local needs);
- Demonstrated ability to work with diverse client populations affected by HIV, including persons with mental and behavioral health conditions;
- Experience working with clients and navigating health systems; and
- A client-centered orientation.

Replication Tips for Intervention Procedures and Client Engagement

Successful replication of the CBSI intervention involves building and sustaining relationships, establishing clear surveillance and linkage processes, and researching statutes.

- *Build and Sustain Relationships:* Data-informed interventions involve various stakeholders, including clinic and health department staff. Client-level data sharing can advance both local and national efforts to improve the health outcomes of people with HIV who are out of care. Systems and institutions may work in “silos” for various reasons (e.g., funding restrictions, statutes governing data sharing). By fostering partnerships between health departments and HIV clinics, the CBSI intervention and similar data-informed models can overcome “siloeing” and increase the impact of relinkage and retention efforts.

To create and sustain synergy between the health department and your clinic, consider:

- Researching how your local or state health department has historically worked with your clinic or with similar clinics in your area;
- Connecting with health department staff to ask about current linkage-to-care efforts and health department staff’s willingness to replicate this intervention; and
- Communicating how data-informed efforts, such as a Data to Care program, will benefit the health department’s HIV care and prevention efforts, as well as your clinic’s need for this collaboration at your clinic. A Data to Care program is a public health strategy that uses HIV surveillance data and other data sources to identify people with HIV who are not in care, link them to appropriate medical and social services, and ultimately support the HIV care continuum.
- *Establish Clear Surveillance and Linkage Processes:* The CBSI intervention has two specific components focusing on (1) surveillance and (2) relinkage. Clinics can



effectively plan how to identify and relink clients who are out of care by developing actionable steps. To create these steps, clinic staff should have internal conversations about organizational goals and about operationalizing a data-informed framework that considers their existing infrastructure, funding streams, and resources.

- *Research Statutes.* Data privacy remains a key priority for HIV surveillance systems. As a result, local statutes that govern client-level data sharing between health departments and clinics may differ. Jurisdictions such as Washington State allowed HIV data sharing between health departments and medical care providers, which helped facilitate this intervention. Before implementing the intervention, explore statutes in the host jurisdiction and assess whether the law permits the local or state health department to share client-level HIV data to promote and enhance linkage and retention for people with HIV.

Securing Buy-In

This intervention's success is contingent on its acceptability to clients, medical care providers, and health departments. It is important to incorporate the perspectives of people with HIV who may receive relinkage services, staff engaged in service delivery, and health department surveillance teams. Assessing clients' and staff's perspectives about data-based surveillance interventions can also help further inform activities and build community support.

For these reasons, the Madison Clinic conducted qualitative interviews with clients and providers in 2010. The clinic interviewed 20 people who had HIV RNA levels >10,000 copies/mL in 2009-2010 and were randomly selected from HIV surveillance data. The clinic also interviewed 15 medical care providers.⁹

The interviews revealed that clients almost uniformly considered the intervention to be promising. More specifically, clients expressed an interest in receiving more linkage assistance, such as consistent follow-up and being connected to comprehensive services and quality care.⁹ Some providers were eager to get clients back into the clinic and to develop a routine for identifying clients who were at risk of falling out of care. Other providers were concerned about information security and client perceptions of health surveillance systems.

Results from these interviews were presented to the Madison Clinic's planning council and community advisory board. These presentations focused on:

- How clinic-based and surveillance-informed activities would work;
- Staff roles; and
- The current standard of care (e.g., the CD4 count threshold that would warrant staff reaching out to clients).



Conducting assessments with clients and medical care providers may enable clinics to witness how affected communities and medical care providers accept the intervention. To promote engagement in HIV care, clinics should conduct assessments with a subset of the client population to gather their perspectives on health department-initiated contact.

Relationships with clinic leadership and leadership support are also integral to the success of the intervention. These relationships are especially useful if challenges arise that a data manager or linkage specialist cannot address. Leaders can vouch for the project as an important initiative that deserves support. Additionally, having strong relationships with clinic staff allows the linkage specialist to cross-collaborate and gather information about clients who may be on a provider's panel.

When staff connect with external social service organizations that offer wraparound services, clients receive several benefits. These connections allow staff to leverage existing relationships with providers and to tailor referrals based on the client's life experiences and needs.

Overcoming Implementation Challenges

The CBSI intervention is multifaceted, and its implementation can be complex. Anticipated challenges, as well as possible solutions, are noted below.

- **Lack of Administrative Support:** Seek ways to sustain linkage activities. If activities are not supported and sustained, they may cease to be an organizational priority due to the amount of time and effort required to relink clients into care.
- **Barriers to Care:** To address interconnected social determinants of health that can result in barriers to care, organizations should consider offering gift cards and connecting with local service agencies.
- **Data-Sharing Challenges:** Gathering information about current clinic policies, as well as lessons learned from other interventions, can improve the data-sharing process.



- **Lack of Referrals:** Educate doctors about the intervention to facilitate referrals.
- **Data Management:** Use a database that allows staff to gather, extract, and analyze client-level data.
- **Staff Burnout:** If the linkage specialist is unable to successfully link clients to care despite dedicated efforts, they may feel discouraged and disappointed. Find ways to increase staff morale and highlight their work to connect people with HIV to care. Conduct consistent check-ins with staff to address barriers in real-time and prevent burnout.
- **Undefined Staff Roles:** Be clear on roles and responsibilities and how these may sometimes overlap. For example, note who communicates with the health department if a client cannot be reached and who will manage and update the list of out-of-care clients.
- **Delayed Data Sharing:** Ensure that data extraction and surveillance data matching are conducted in a timely manner. By improving the timeliness of data sharing, organizations can ensure that, for example, they have the most up-to-date client information, which can facilitate prompt relinkage efforts.¹¹
- **Long-Term Goals:** While completion of a medical visit is considered a marker for relinkage, it is beneficial to focus on sustained engagement in care. The linkage specialist can work with medical providers to collect information about barriers to sustained engagement in care to address those factors with clients.
- **Limited Engagement:** Matching and outreach activities may result in slight improvements in engagement and retention outcomes among the client population. However, it is important to recognize the value of engaging any number of people with HIV and to not solely rely on absolute numbers.

Adaptation of the Original Intervention

In response to Seattle-King County’s commitment to reach the United Nation’s HIV 90-90-90 goals¹² and the limited impact that two HIV care re-engagement interventions—including the CBSI intervention—had on achieving viral suppression, the CBSI intervention developers explored alternative service delivery models. They also determined that achieving additional improvements in viral suppression required a more significant focus on individual and structural-level changes.¹² They, therefore, used the CBSI intervention as a catalyst for the development of differentiated models of care at the Madison Clinic.

The clinic created the Moderate assistance (Mod) and Maximum assistance (Max) clinics to address barriers to HIV care caused by health care systems factors (e.g., appointment availability, need for advanced scheduling) and psychosocial barriers (e.g., substance use, unstable housing, mental and behavioral health disorders). Clients who are unsuccessfully relinked to care through clinic outreach efforts are referred to one of these clinics.

The Mod Clinic follows a flexible, walk-in model. A percentage of clients are seen in a triaged fashion. Clients can drop in to the Mod Clinic for acute needs and are offered expanded levels of care. Clients who achieve viral suppression but miss ongoing appointments can choose to visit the Mod Clinic, which offers a walk-in option for ART prescriptions.

The Max Clinic follows a high-intensity, low-threshold, incentivized care model to address the needs of clients with complex medical and social needs. It serves the subset of clients who:

- Were not virally suppressed at the time of their last viral load test,
- Are no longer taking ART, or
- Are not engaged in care after low-intensity outreach and support were offered.¹³

Table 2 — Adaptation Table



| Original Model | Adaptation | Rationale |
|--|-------------------------------|---|
| Clinical-Based Surveillance-Informed Uniform Model of Care | Differentiated Models of Care | <p>Re-engagement services did not successfully reach people with unstable housing, substance use disorders, and psychiatric disorders.</p> <p>At the time of enrollment, most Max Clinic clients were actively using drugs or harmful levels of alcohol (86 percent), had received a diagnosis of a psychiatric condition (71 percent), were unstably housed (65 percent), and had a history of incarceration (42 percent).</p> |

The Max and Mod clinics are novel interventions that aim to meet the health and social needs of people with HIV who are out of care. The clinics also aim to help clients achieve sustained engagement in care and viral suppression. Both clinics show the possibilities in the realm of HIV care and how comprehensive, tailored services can improve relinkage and overall health outcomes.

Table 3 — Components of the Max Clinic That Differ From the Standard-of-Care Clinic Approach

| | |
|--------------------------------|--|
| Low-barrier access | <ul style="list-style-type: none"> • Walk-in access to medical care 5 afternoons a week • Walk-in access to medical and nonmedical case management 5 days per week • Text message and direct phone access to case managers |
| High-intensity support | <ul style="list-style-type: none"> • Case managers provide care coordination, navigation, and support^a • Medical case managers have a low case load (~50 patients) compared with standard of care (~150 patients) |
| Incentives | <ul style="list-style-type: none"> • Food vouchers worth \$10 up to once weekly • Snacks available at each visit • No-cost bus passes to provide unrestricted transportation support • Cell phones^b • Cash incentives for visits with blood draws^c • Cash incentives for viral suppression^d (HIV RNA < 200 copies/mL) |
| Intensified care coordination | <ul style="list-style-type: none"> • Case managers serve as primary contacts for patients, providers, and for coordination between Max Clinic and other agencies, including: <ul style="list-style-type: none"> • Release planning team in King County jails • Housing and mental health case management agencies • Day program with medication adherence support • Office-based opioid treatment nurse managers and methadone providers |
| Transitional care coordination | <ul style="list-style-type: none"> • Staff receive automated alerts when patients are seen in the emergency room or admitted to a hospital in the University of Washington Medicine system • Max Clinic staff work with inpatient medical teams to plan transition to outpatient care and day-of-discharge Max Clinic visit |

^a Public health disease intervention specialists who specialize in HIV care re-engagement.

^b Patients received cell phones if needed only in the first 2 years of the intervention.

^c During the period of this analysis: \$50 up to once every 2 months; at the time of this report: \$25 up to every 2 months.

^d During the period of this analysis: \$100 up to once every 2 months and a 1-time \$100 bonus for the third consecutive suppressed viral load; at the time of this report: \$50 up to once every 2 months.

Reprinted from Dombrowski, J.C., Galagan, S.R., Ramchandani, M., Dhanireddy, S., Harrington, R.D., Moore, A., Hara, K., . . . Golden, M.R. (2019). HIV care for patients with complex needs: a controlled evaluation of a walk-in, incentivized care model. *Open Forum Infectious Diseases* 6(7): ofz294. Copyright 2019 Oxford University Press. Reproduced without modification under Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License <https://creativecommons.org/licenses/by-nc-nd/4.0/>. Full text of article available at <https://academic.oup.com/ofid/article/6/7/ofz294/5523775>.

Table 4 — Intervention Outcomes



| Original Model ^a | Adaptation ^b |
|---|--|
| <ul style="list-style-type: none"> • 15 percent of clients relinked to care • 20 percent of clients contacted by the linkage specialist • 42 percent of clients relinked to care and virally suppressed (historical controls) • 43 percent of clients relinked to care and virally suppressed (intervention cohort) | <ul style="list-style-type: none"> • Pre-to-post viral suppression improved in both Max Clinic clients and standard-of-care control-group clients: <ul style="list-style-type: none"> • Max Clinic clients: From 20 percent to 82 percent (P < .001) • Historical controls: From 51 percent to 65 percent (P = .04) • Max Clinic clients were > 3 times as likely as controls to achieve viral suppression (after adjustment for differences in unstable housing, substance use, and psychiatric diagnoses) |

^aBove, J. M., Golden, M. R., Dhanireddy, S., Harrington, R. D., & Dombrowski, J. C. (2015). Outcomes of a clinic-based surveillance-informed intervention to relink patients to HIV care. *Journal of Acquired Immune Deficiency Syndromes (1999)*, 70(3), 262–268. <https://doi.org/10.1097/QAI.0000000000000707>

^bDombrowski, J. C., Galagan, S.R., Ramchandani, M., Dhanireddy, S., Harrington, R. D., Moore, A., Hara, K., Golden, M. R. (2019). HIV care for patients with complex needs: a controlled evaluation of a walk-in, incentivized care model. *Open Forum Infectious Diseases*, 6(7), July 2019, ofz294. <https://doi.org/10.1093/ofid/ofz294>

Note: Mod Clinic outcomes were not completely evaluated or published at the time this manual was developed.

Promoting Sustainability

To successfully sustain this intervention, project outcomes must be consistently monitored and evaluated. Surveillance data-based programs require significant resources. These efforts can be evaluated by focusing on the number of clients who are ultimately relinked to care. To do this, complete ongoing process and outcome evaluations that include documentation of the following:

- Numbers of cases closed out by the linkage specialist;
- Number of clients who are truly out of care;
- Estimated number of clients whom intervention staff think would have re-engaged in care without the intervention; and
- Number of clients linked to care as a result of the intervention.

By taking proactive steps to measure the success of relinkage efforts, your clinic can identify areas of improvement that can increase the number of clients linked to care and address any barriers to care. Examples of potential strategies for improvement include dedicating more time to exploring the in-patient list and focusing on clients who are no-shows for appointments. You can also gather feedback from linkage specialists, providers, staff, and directly from clients in various ways (e.g., group or individual check-ins, surveys). By creating a consistent and intentional feedback loop, you can ensure that outreach efforts are effective and that concerns are prioritized and addressed as they arise.

The Madison Clinic used retention, the completion of two or more visits that are three or more months apart, as an outcome measure during its evaluation study.

These evaluation approaches can help you explore innovative and data-informed strategies to adjust the intervention, increase its impact, demonstrate how the intervention is working, and emphasize to stakeholders the importance of clinic-health department collaboration.

SWOT Analysis

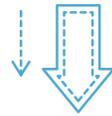
SWOT is an acronym for Strengths, Weaknesses, Opportunities, and Threats. A SWOT analysis is a structured planning method that can assess the viability of a project or intervention. By conducting a SWOT analysis before an intervention, organizations can proactively identify challenges before they occur and think through how to best leverage their organizational strengths and opportunities to improve future performance. A SWOT analysis of the CBSI intervention at the Madison Clinic identified the following:



STRENGTHS

The intervention will increase relinkage and retention outcomes for clients who are out of care by:

- Forming a centralized system that bridges surveillance and clinic data,
- Filling gaps in medical records that contribute to health inequities,
- Presenting the health department or the clinic staff as resources for clients who are out of care,
- Creating a manageable caseload based on staff resources,
- Establishing strong relationships between clinic and health department staff,
- Demonstrating value-added for the clinic as a result of having a staff member (i.e., the linkage specialist) who is specifically working to familiarize themselves with clients who were at least marginally engaged in care; and
- Facilitating the extraction of a client's medical record and assessment of recent visits.



WEAKNESSES

Agencies will find it challenging to implement the CBSI intervention without:

- Data systems in place to collect, extract, and transmit client-level data,
- Dedicated staff with backgrounds in HIV, linkage, and EHR data systems,
- Resources for staff to contact clients (e.g., cell phones, social media platforms),
- Meaningful engagement from clinic leadership and providers,
- Relationships and ongoing communication with local social service agencies,
- Monitoring and evaluation measures and processes,
- Local data-sharing statutes or agreements with local or state health departments, and
- Ability to promptly schedule an appointment for a client once contact is made.



OPPORTUNITIES

The CBSI intervention offers opportunities to:

- Match out-of-care client lists with surveillance data,
- Leverage the broader healthcare landscape if the clinic is connected to a hospital system (e.g., emergency health department, in-patient units),
- Request more data to fill potential gaps in demographic information, and
- Streamline linkage and retention services using one linkage specialist who is connected to the broader clinical team.



THREATS

Threats to the success of the CBSI intervention include:

- Difficulty securing funding to sustain data systems and services,
- Limited staff capacity due to competing priorities and insufficient FTEs,
- Poor staff retention due to burnout,
- Inability to address complex barriers to care due to interconnected social determinants of health,
- Lack of a centralized system that fosters engagement between different organizations, and
- Reallocation of funding to meet other pressing and emerging needs.



Conclusion

To curtail the HIV epidemic and improve health outcomes for people with HIV, the Madison Clinic implemented the CBSI intervention, allowing clinics and health departments to work collaboratively and intentionally to address linkage and retention gaps. By leveraging surveillance data to more efficiently and accurately identify clients who are out of care and developing comprehensive mechanisms to link people with HIV into care, clinics play a pivotal role in improving health outcomes for marginalized populations. Moreover, surveillance-informed activities contribute to national efforts to end the HIV epidemic. They also demonstrate how enhanced data infrastructure within public health care systems advances health equity for people with HIV. Further, in adapting the CBSI intervention's linkage efforts to reduce service delivery gaps for clients with complex barriers to care, clinic providers and staff have more holistically addressed clients' interconnected health and social needs.

The CBSI intervention showed modest but statistically significant effectiveness in linking people with HIV to care. Compared with the historical cohort, the time to relinkage was shorter among clients in the intervention cohort (adjusted hazard ratio = 1.7 [1.2–2.3]), and a greater proportion was relinked to care (15 percent vs. 10 percent).¹ The second iteration of the intervention, which included the creation of a Max clinic, a clinic designed to engage patients who have extensive barriers to HIV care, showed significant improvements in viral suppression outcomes pre-and post-intervention (from 20 percent to 82 percent; $P < .001$) compared with historical controls (51 percent to 65 percent; $P = .04$).¹³

Additional Resources

Ryan White HIV/AIDS Program Fact Sheet

hab.hrsa.gov/sites/default/files/hab/Publications/factsheets/program-factsheet-program-overview.pdf

Ryan White HIV/AIDS Program Services: Eligible Individuals & Allowable Uses of Funds Policy Clarification Notice 16-02

hab.hrsa.gov/sites/default/files/hab/program-grants-management/ServiceCategoryPCN_16-02Final.pdf

HIV National Strategic Plan

hiv.gov/federal-response/national-hiv-aids-strategy/national-hiv-aids-strategy-2021-2025

Cost Analysis Summary for the Clinic-Based Surveillance-Informed Intervention

[CIEhealth.org/intervention/clinic-based-surveillance-informed/#resources](https://ciehealth.org/intervention/clinic-based-surveillance-informed/#resources)

(Click on link under Cost Analysis section)

CIE Cost Analysis Calculator

[CIEhealth.org/innovations](https://ciehealth.org/innovations)

Prioritizing an Out of HIV Medical Care List

<https://ciehealth.org/intervention/clinic-based-surveillance-informed/#resources>

(Click on link under Resources section)

Endnotes

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