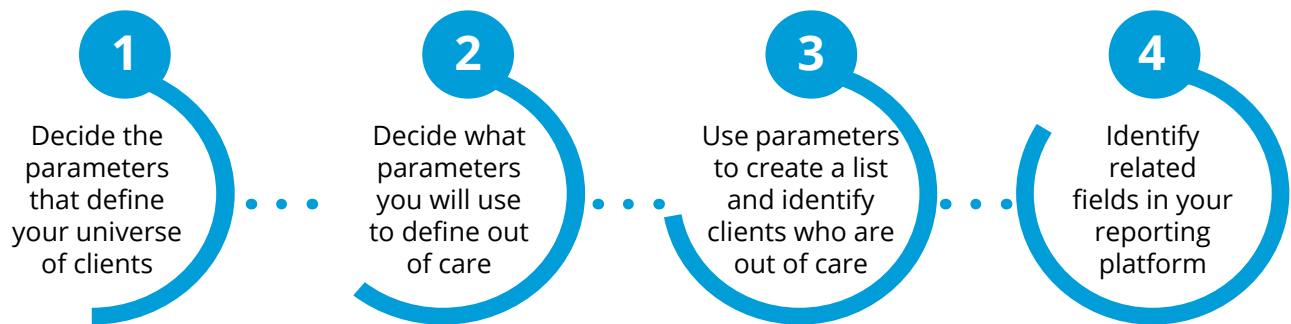


Running an HIV Out-of-Care List

Introduction: This guide will help program or data managers who are part of an organization that provides clinical services to create and maintain a list of clients with HIV who may be out of care.

Overview: To create and run an HIV out-of-care list regularly, your organization must have an electronic system or reporting platform, such as an electronic health record (EHR). The information in that electronic system must be stored in a “queryable” or structured form so that it can be used in reports. In other words, the data need to be in a table format with rows and columns. Once you have that, follow these four steps.



1. Decide on the parameters that define your universe of clients.

The first step in developing an HIV out-of-care list is to decide who should be included in your client “universe.” This universe is made up of all clients you are responsible for retaining in care. In many cases, this will include everyone who is receiving HIV care from your program. If you are part of a large organization, there may be many clients with an HIV diagnosis who are getting services elsewhere in the organization. For example, if you only want to focus on clients that are receiving primary care and/or HIV specialty care at your organization, you may need to exclude patients that are only receiving non-HIV-related specialty care (e.g., cardiology, oncology), if those providers use the same EHR or data system.

What timeframe will you use to determine who ‘your’ clients are?

In other words, which group of clients will you review to see if its members have met the criteria for ‘retained in care’? For example, do you want to include clients who have accessed services (e.g., medical visits, labs, case management visits) in your clinic/practice in the last 18 months? 24 months?

- Make a note of the date range you will use based on the length of time you decide on, such as 18 months; 1/1/2020–6/1/2021.

Will you include clients seen at all locations or departments for any visit type? Or only clients who have accessed services in your sexual health, HIV, or infectious disease clinic? Also, will you include all clients in the data system who have a diagnosis of HIV or AIDS, or limit your universe to clients who receive HIV care from your program? For example, you might select from the following:

- Visit type: all; all medical; all primary care or preventive; all case management; all HIV-related labs.
- Decide if visit(s) done via telehealth will be included or excluded.
- Facility/site ID or location: all; primary care locations; sexual health or infectious disease clinic locations.
- Providers: all providers; all medical providers; all medical providers who provide HIV care (with prescribing privileges).
 - If you have residents, interns, nurse practitioners, or physician assistants who see clients for clinical visits, you will need to determine if they (and the clients they have seen) should be included.

2. Define your parameters for “retained in care” and “out of care.”

In Step 1, we determined the group of clients for which we are responsible for keeping engaged in HIV care. In Step 2 we are asking: of those clients, who has been retained in care and who is out of care? See the tip box for the definitions to consider as you are deciding.



Below is a list of definitions of “**retention in care**,” as identified in the [National HIV Curriculum](#). Because every organization is different, not every definition will be relevant. Your team should identify which definition makes sense to use based on the context of your organization and services.

The [Health Services and Resources Administration \(HRSA\) HIV/AIDS Bureau](#) defines retention in care as a person who has had at least two HIV medical care encounters at least 90 days apart within a 12-month measurement year. At least one of the two HIV medical care encounters needs to be a medical visit with a provider with prescribing privileges.

An **HIV medical care encounter** is defined as a medical visit with a provider with prescribing privileges or an HIV viral load test.

Similarly, the [Institute of Medicine](#) has defined retention in HIV medical care as at least 2 medical visits every 12 months, with a minimum of 90 days between visits.

[Centers for Disease Control and Prevention \(CDC\)](#) defines retention in HIV medical care as documentation of at least 2 CD4 cell counts or viral load tests performed at least 3 months apart during the year of evaluation. The CDC also refers to this as continuous HIV medical care.

What timeframe will you use for “retained in care” and “out of care?”

- Typically, clients who have not been seen for care, labs, or testing in either 6 or 12 months will be considered “out of care.”
- The Massachusetts Department of Public Health currently uses a 6-month timeframe, but there is variation across jurisdictions and agencies. Consider the following:
 - Using a 6-month timeframe may result in a list that includes many clients who are on an annual schedule for care.
 - Using a 12-month time frame may generate a list that misses clients who should be coming in more frequently.

What type(s) of visit will you use to show that the client has been “retained in care” in the timeframe defined above?

- Any office or telehealth visit?
- Any office visit at specific facility/ies, location(s), or department(s)?
- Any office visit with specific providers (such as those who can prescribe)?
- Any HIV viral load test performed in this facility/health system or in the client record?

3. Apply parameters to identify clients who are retained in care and clients who are out of care.

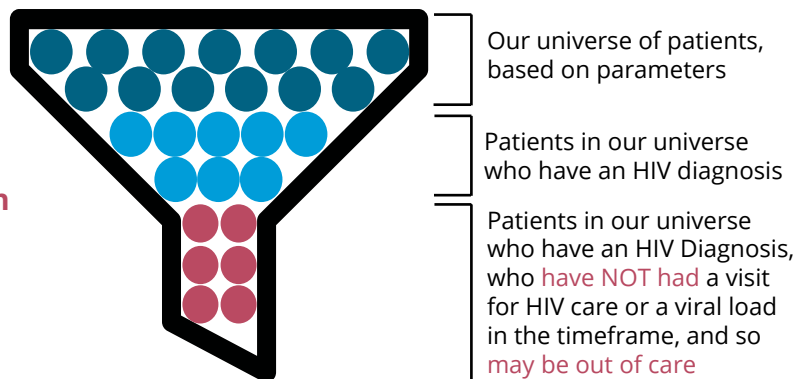
Think of this as a funnel (as in the image below), where you start with the group of clients for whom you are responsible for retaining in care. Then narrow down the list of clients, leaving only those who may be **out of care** at the bottom.

Summarize and implement the parameters from Step 1 that define the client universe.

Begin with a list of clients who have diagnosed HIV and have had a medical visit at your clinic in a specific period of time (e.g., the past 18 months).

Summarize and implement the parameters from Step 2 to determine who has been retained in care and who is out of care.

Include clients (from the list of clients you have identified for retention in care) who do not have a visit or referral for HIV medical care and/or viral load within the period of time you have defined (6 months for example) nor an upcoming appointment in the HIV out-of-care list. To determine whether a visit is for HIV medical care, look to see that there is a diagnosis of HIV recorded on the visit.





4. Identify related functionality and fields in your reporting system.

If you are creating your own out-of-care list using reporting tools (e.g., MySQL, Crystal Reports, Business Objects), identify the fields that contain your parameters. If you are working with your information technology (IT) team to set up a report, ask about functionality and standard definitions. For example, some EHRs allow you to filter clients by site and provider, while others have registry or population health functionality that allow you to set up a cohort of clients to follow based on selected characteristics. See the pink Value Sets box on the next page for helpful standard definitions that might be used for some of these reports.

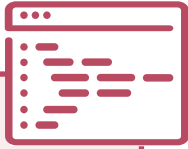

To determine who of these clients are out of care, the report will need to list client information. Consider creating it in Excel or another format that you can filter to help track follow-up information when you contact clients who are out of care. Your report could include these example fields: first name, last name, DOB, age, MRN, assigned physician, date of HIV diagnosis, date of last appointment, last appointment provider, upcoming appointment, upcoming appointment provider, viral load date, and viral load value. See sample report formats at the end of this document.

Tips for getting this report from your IT or quality team:

- Tell your IT, quality, or help desk staff what the list is for, how it will be used, and what you want it to be called so that you can find it once it has been created.
- Ask the help desk for access to the reports with your final specifications.
- Larger organizations may have centralized access and support for reporting tools. Ask IT or the help desk for assistance and access. Be patient with this process. It may require some trial and error.
- Identify who in your or a related department knows the data criteria well. Ask them about what data elements are called and how they can be identified or filtered. This will help you communicate when you need tech support.

Tips for reviewing the list for accuracy and improvement:

- Review the list with providers, case managers, and other care team members who may be able to provide insight on accuracy. Are these clients truly out of care? If not, why are they showing up in our list? You may end up refining your report parameters as a result of these conversations.
- Convene teams to review inaccurate data and discuss any trends. Identify opportunities to improve data capture and reporting going forward.



Health IT vendors or analysts often use [value sets](#) to identify clients associated with a specific clinical concept. A **value set** is a group of standardized codes maintained centrally in the [Value Set Authority Center](#), which you can create a free account to access.

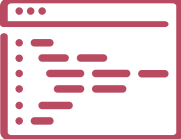
Here are value sets to help you identify clients with HIV who are in care in an EHR:

To identify clients with HIV: diagnosis: indicators of HIV value set ([2.16.840.1.113762.1.4.1056.54](#))

To identify clients with a visit: encounter, performed: office visit value set ([2.16.840.1.113883.3.464.1003.101.12.1001](#)). *Note that this value set typically does not include visits done via telehealth.*

To identify clients who had a viral load: HIV viral load ([2.16.840.1.113883.3.464.1003.120.11.1004](#))

Once registered, you can review each or download an Excel file with all codes included in a given value set.



Sample Reports

This report example is limited to clients with no CD4 count or viral load test results in the past 6 months. It includes both information that might be pulled from the EHR (in the first 6 columns) and information filled in when using the list for review and follow up (in the remaining columns).

The Notes field is used to indicate important information not captured in one of the columns, such as incarcerated; moved out of state; deceased; institutionalized; entered substance abuse program; lost to follow-up (e.g., >4 months since contact, no pending appointment, and multiple attempts at contact).

Site Name:													
Date Report Created:													
<i>No new CD4 or VL in 6 months</i>													
Client Information			Physician Information			Last Line List (if applicable)		In care		Out of care			
Client First Name	Client Last name	DOB	Physician First name	Physician Last name	Date of Last Reported Lab	Date of last line list appearance	Notes from last line list	Reasons not out of care	If had lab, date of lab	Attempted to contact client?	Contacted client?	Scheduled an appointment?	Notes

This example shows information that can be pulled directly from the EHR, with the exception of the Lost Category, which staff complete manually.

L name	F name	DOB	MRN	Last date service	Pending appt	Provider	Lost category	Last VL	Notes
						LIEDER	DECEASED		
						BOWERS	DECEASED		
						STEDMAN	DECEASED		DD:
						TONG	DECEASED		
						STEDMAN	DECEASED		DD:
						EFFINGER	INCARCERATED		
						STEDMAN	INCARCERATED		
						EFFINGER	LOST		DNR
						WILSON, MEARS	DECEASED		
						BOWERS, BAKER	LOST		
						LIEDER, LOMBARDI	LOST		
						BOWERS, BAKER	LOST		
						LIEDER	LOST		

