Veterans Health Administration (VHA) HIV Reporting Toolkit

Toolkit for HIV case reporting from VHA facilities to state, tribal, local, and territorial (STLT) public health agencies in the United States
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VHA = Veterans Health Administration, STLT = State, tribal, local, and territorial
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Purpose of the Reporting Toolkit

In response to the U.S. Department of Health and Human Services (DHHS) initiative to reduce the number of new HIV infections by 90% by 2030, the Centers for Disease Control and Prevention (CDC) has worked to identify and address gaps in the national capacity to respond to HIV outbreaks, manage HIV data, and share data across entities.

The purpose of this toolkit is to inform state, tribal, local, and territorial (STLT) public health agencies and Veterans Health Administration (VHA) medical centers on best practices for HIV case reporting to improve VHA HIV reporting to public health agencies.

Toolkit Development

This toolkit was created by the Council of State and Territorial Epidemiologists (CSTE) in collaboration with various stakeholders from state, tribal, local, and territorial (STLT) public health agencies and CDC. VHA was invited to participate but did not contribute to the content of this toolkit.

This toolkit was informed by the 2018 CSTE VHA HIV Reporting Assessment (readministered in 2022), key informant interviews with health department and CDC stakeholders conducted in 2022, and CSTE stakeholder input.
Extendibility

While this toolkit is focused on the importance of reporting HIV, the information contained may also be used to advance reporting by the VHA for all reportable conditions to STLT public health agencies.

Some of the tools referenced in this toolkit, such as electronic case reporting (eCR) and electronic laboratory reporting (ELR), are likely already operational in your jurisdiction. HIV requirements can be incorporated into these existing reporting streams or frameworks.

- Leveraging existing reporting streams can reduce burden on both VHA facilities and STLT public health agencies.
- VHA facilities should take advantage of automated tools to support data modernization efforts, which improve timely and secure access to data.
In the 2022 CSTE assessment of HIV reporting practices, health departments reported on 75 VHA facilities and the results showed that:

- **37%** of the facilities never report new HIV diagnoses to the health department*
- **33%** of the facilities never report new patients with existing HIV diagnoses to the health department*

The previous assessment conducted in 2018 included 63 VHA facilities and showed similar results:
- 34% of the facilities never report new HIV diagnoses to the health department
- 43% of the facilities never report new patients with existing HIV diagnoses to the health department

*This includes both proactive reporting to health department and reporting initiated by health department outreach.

- Always
- Most of the time
- Sometimes
- Not sure
- Never
Importance of HIV Reporting

Approximately 1.2 million people in the U.S. live with HIV, and more than 30,000 new HIV infections are diagnosed each year in people ages 13 and older.

STLT HIV surveillance programs collect the primary data used to monitor the extent of HIV infections in the US. They are used widely to monitor the impact of HIV in our communities and evaluate HIV prevention and care efforts aimed at reducing infections and ultimately improving the health of people with HIV. Timely and accurate HIV case reporting helps both the public health system and the patient.

Coordinating efforts to provide timely treatment to HIV patients across multiple stakeholders and healthcare systems helps to make programmatic and policy-related decisions to:

- Prevent new HIV infections
- Improve HIV-related health outcomes for people with HIV
- Reduce HIV-related disparities and health inequalities
Importance of HIV Reporting to Public Health

Timely and accurate HIV reporting helps the public health system:

• Improve HIV surveillance
• Optimize resource allocation
• Decrease disease transmission
• Enhance prevention efforts
• Detect HIV transmission clusters
• Improve timeliness of data dissemination
• Determine care outcomes such as linkage to care, retention in care, and viral suppression
Timely and accurate HIV reporting benefits patients and helps their healthcare providers\textsuperscript{3,4}:

- Link newly diagnosed individuals to care
- Monitor outcomes to identify gaps in services
- Activate care planning
- Initiate treatment to achieve viral suppression
- Re-engage people in medical care
- Form risk-reduction plans
HIV Data Surveillance Overview

There are 2 general types of HIV reporting:
- Laboratory result reporting [passive or active]
- HIV case reporting [passive or active]

HIV cases that must be reported for surveillance purposes:
- New diagnoses and existing patients new to care
- Previously diagnosed HIV cases in new patients [e.g., patients who have relocated from another state]
HIV Surveillance Data Flow

People living with HIV and persons not yet diagnosed with HIV

VHA facilities
(hospitals, medical centers, and other)

HIV tests

Laboratories
(in-house or outsourced)

HIV surveillance
HIV case & lab reporting

STLT public health agencies
(HIV surveillance program)

Disseminate and summarize state data

Surveillance reports

Technical assistance

National HIV Surveillance System

Council of State and Territorial Epidemiologists
What Governs VHA-STLT Partnership?

VHA-STLT health agency partnership is governed by:

- **VHA directives and publications**
  - VHA Directive [1304](#) "National Human Immunodeficiency Virus Program"
  - VHA Directive [1131](#) “Management of Infectious Diseases and Infection Prevention and Control Programs”
  - VHA Directive [1605.01](#) “Privacy and Release of Information"
  - VHA Privacy and Release of Information Notice of Privacy Practices NOPP

- **State reporting laws** (see Reporting: HIV Laboratory Tests)

Cooperation between VHA & STLT health agency is established by:

- Building and maintaining positive working relationships between STLT health agency staff and VHA facilities
- Creating, signing and adhering to a reporting agreement called a “written request letter” (as per VHA Directive 1605.01)
VHA Directive 1131 “Management of Infectious Diseases and Infection Prevention and Control Programs” states:

“VA medical facilities are to report on the designated reportable diseases according to the laws, regulations, and policies of States and territories and to follow VHA Directive 1605.01 and other applicable policies and laws on release of information”

“VHA has voluntarily chosen to report reportable infectious diseases when legally permitted as a measure of sound public health practice”

VHA Directive 1605.01 “Privacy and Release of Information” states:

“VHA may report a patient’s individually-identifiable health information, excluding 38 U.S.C. 7332-protected information, to States for public health purposes when there is a signed standing written request letter between the VHA health care facility and the State that covers the public health reporting of a specific infectious disease or other information, such as vaccinations or vital statistics”
VHA "Privacy and Release of Information Notice of Privacy Practices NOPP" states:

"Public Health Activities. We may disclose your health information without your authorization to public health and regulatory authorities, including the Food and Drug Administration (FDA) and Centers for Disease Control (CDC), for public health activities. This includes disclosing your information for:

- Controlling and preventing disease, injury, or disability, Reporting vital events such as births and deaths.
- Reporting communicable diseases such as hepatitis, tuberculosis, sexually transmitted diseases & HIV.
- Tracking FDA-regulated products.
- Reporting adverse events and product defects or problems.
- Enabling product recalls, repairs or replacements"
HIV REPORTING RECOMMENDATIONS
Categories of Recommendations

- Reporting
  - Case reporting
  - Lab reporting
  - Technology

- Documentation
  - Standing written request letter

- Staffing & Training
  - Designated staff
  - Staffing changes
  - HIV reporting standards

- Communications
  - VHA engagement
Reporting HIV Cases

Overview

Case reporting to health departments is a crucial element of HIV surveillance that promotes understanding of HIV morbidity and mortality in the U.S.

STLT HIV surveillance programs confidentially collect, analyze and disseminate de-identified data on HIV infection to inform federal agencies, health departments, community-based organizations, nonprofit organizations, academic institutions and the public on the most recent information on HIV in the U.S.

Systematic and reliable data collection of new and existing HIV cases is a vital part of the assessment of infection prevalence, resource allocation, service planning, and general guidance for public health action at the federal, state, and local levels. Systematic and reliable data collection also helps STLT HIV prevention and surveillance staff conduct activities such as cluster detection and response.
Despite the VHA’s voluntary agreement to report infectious diseases to health departments as a sound public health practice, [most] VHA facilities [rarely] report new HIV cases or information on new patients with existing HIV diagnoses.

As a result, health departments are not given critical HIV-related information unless they actively solicit information from VHA facilities.

The Adult HIV Confidential Case Report Form (ACRF) is a key tool for VHA facilities to communicate HIV cases to departments of health, however, proper and complete preparation of the report is uncommon.
Reporting HIV Cases

Recommendations

➔ **PREFERRED** - proactively report required information to health departments using the

- Adult HIV Confidential Case Report form (ACRF) (CDC 50.42A/CDC 50.42C), or
- State-specific ACRF form (if one exists)
- Electronic Case Reporting (eCR)

Each form or report at a minimum must contain: last name, date of birth, ethnicity, HIV diagnosis information (if indicated), race, birth sex, (+ state case number and vital status for health department reporting to CDC) for existing patients with newly diagnosed HIV infection and for new patients with previously diagnosed HIV (e.g., persons who have relocated to a new state).

➔ **ACCEPTABLE** - consistently notify health departments about all patients newly diagnosed with HIV infection and all patients with previously diagnosed HIV; the health department then follows up and completes the Adult HIV/AIDS Confidential Case Report form.
A note on confidentiality & privacy of HIV Case Reports sent to CDC

Reporting of HIV cases from health departments to CDC is done confidentially and securely. Completed **Adult HIV Confidential Case Report forms (ACRF)** are **NOT** sent to the CDC with patient identifying information. These forms are transferred electronically from health departments to the CDC via secure data network using compatible or standardized computer software (Secure Access Management Services (SAMS) **WITHOUT** patient identifiers.

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**Patient Identification (record all dates as mm/dd/yyyy)**

- **First Name**
- **Middle Name**
- **Last Name**
- **Last Name Soundex**
- **Alternate Name Type** (ex: Alias, Married)
- **Current Address, Street**
- **Address Date**
- **City**
- **County**
- **State/Country**
- **ZIP Code**
- **Phone**
- **Medical Record Number**
- **Other ID Type**
- **Number**
Reporting HIV Laboratory Tests

Current Situation

Some VHA facilities outsource HIV testing to commercial labs whereas others test samples within their own facilities.

Laboratory data (including CD4+ T-lymphocyte (CD4), viral load test results, and HIV nucleotide sequence data) is an essential component of HIV surveillance programs. Lab data can be used to help monitor patients and evaluate whether they are receiving appropriate care.

[Most] VHA facilities that outsource testing do not actively participate in communicating HIV laboratory test results to health departments. HIV test results from commercial labs are passively communicated to health departments due to state laws and regulations on infectious disease surveillance.

VHA facilities that perform in-house HIV testing rarely report results to health departments. This creates inconsistent and incomplete HIV reporting and negatively affects surveillance, prevention, and care program efforts.
**Reporting HIV Laboratory Tests**

**Recommendations**

➔ **PREFERRED** - electronic reporting of complete HIV laboratory test results to the health department from both (1) tests that have been outsourced and (2) tests performed in-house for all tests indicative of HIV infection and all tests to monitor the progression of HIV infection

- Set timeframes for regular reporting of all HIV laboratory test results via ELR as per [individual State law requirements](#).
- Comply with the technical requirements outlined in [HL7, version 2.5.1](#), (i.e., confidentiality, interoperability, data transfer, data security issues, encryption, ICD & CPT codes, etc.)

➔ **ACCEPTABLE** - non-electronic reporting of complete HIV laboratory test results to the health department from in-house labs (e.g., paper format)

- Set timeframes for regular reporting of all HIV laboratory test results as per [individual State law requirements](#)
- Ensure secure data transfer

ICD = International Classification of Diseases, CPT = Current Procedural Terminology
Overview

Data from the VHA must be transferred using secure methods to health departments.

Technologies that permit secure and confidential data transfer of HIV-related information are crucial to the reporting process. Inadequate technology, user misutilization, and lack of related processes and procedures threaten patient confidentiality.

The CDC uses the Enhanced HIV/AIDS Reporting System (eHARS) for collecting HIV surveillance data securely and confidentially from health departments.

Health departments use various electronic data reporting systems that are compatible with eHARS and comply with the CDC data security and confidentiality guidelines.
Current Situation

There is currently no single standard, secure HIV data-transfer portal or set of generally accepted security and confidentiality procedures between VHA facilities and health departments. Yet all states adhere to a set of minimum guidelines and some states have developed secure data transfer procedures.

All states that share data comply with, at a minimum, the CDC’s National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) Data Security and Confidentiality Guidelines.

Few health departments currently receive HIV surveillance data electronically from VHA facilities.

Health department staff are more likely to obtain HIV-related information from VHA facilities via paper forms, phone calls with VHA staff, or visits to the VHA facility.
Reporting: Technology

Recommendations

Collaborate with health departments to identify a pathway for electronic reporting using one or more of the following:

- Electronic case reporting (eCR)
- A web-based system that outputs a file that can then be transferred from the VHA to the health department
- Electronic files that can be uploaded on a secure site
- Access to VHA medical records by designated health department staff

Train staff to prioritize security of internal data and data from all public health programs and agencies that interact with the VHA.

Investigate and implement technologies and data-transfer procedures used for other infectious diseases for implementation within HIV reporting and surveillance. These include automated electronic laboratory reporting (ELR) and electronic case reporting (eCR) data streams
Overview

Establishing appropriate governance documentation and properly completing relevant reporting forms are essential to a successful VHA-health department relationship.

- A facility-level or Veterans Integrated Services Networks (VISN)-level (in states with multiple VHA facilities) **Standing Written Request Letter** indicates VHA commitment to comply with state public health information-sharing and reporting laws.

- HIV status reporting forms, such as ACRFs, communicate essential information for HIV surveillance, and must therefore be understandable and uncomplicated.

Current Situation

- All VHA facilities do not have a signed Standing Written Request Letter in place that establishes commitment to comply with applicable state data- and information-sharing statutes.
Standing Written Request Letter Template

Microsoft Word Document

Council of State and Territorial Epidemiologists

Recommendation

Per VHA Directive 1605.01, the health department should issue, and the VHA facility should sign, a **Standing Written Request Letter**, which is:

- In writing
- Specifies the public health reporting required and the State law mandating such reporting
- Signed by a qualified representative of the State agency requesting the information

[Insert agency letterhead here]

**[DATE]**

[Insert VA Facility Name]
[Street Address]
[City, STATE Zip Code]

**RE:** Standing Written Request for Patient Information

Dear Medical Center Director:

This agency has responsibilities for protecting the public health or safety pursuant to **[INSERT SPECIFIC AND APPLICABLE STATE LAW]** to investigate or obtain information for the purposes set forth in and authorized by the cited Statute.

As the authorized head of this agency or delegated representative, I hereby request the Department of Veterans Affairs (VA) to report **[INSERT SPECIFIC INFORMATION REQUESTED FROM VA]** for the purpose of **[INSERT YOUR REASON FOR NEEDING THIS INFORMATION]**.

This information will not be utilized for any purpose other than required by law. This agency is aware of the penalty provisions of 38 U.S.C. § 5701(f)(2) which provides a penalty for unauthorized use of names or addresses of Veterans and their dependents not to exceed $5,000 for the first offense and $20,000 for any subsequent offense.

This request shall be valid for a period of three years.

Sincerely,

[Name]
[Insert Agency Head Name]
[Insert Agency Name]

[If applicable, add the delegation of authority letter as an enclosure to sign on behalf of the agency head]
**Current Situation:** There is not always a designated person(s) in charge of HIV case reporting at VHA facilities, causing inefficiencies when HIV STLT surveillance staff reach out to obtain HIV patient information.

**Recommendation for VHA:** At the facility level, the VHA is encouraged to establish a designated point of contact for all HIV case reporting-related inquiries and tasks.

- Recommend to also designate a back-up staff person

**Recommendation for health department:** Create a list of all VHA facilities in the jurisdiction of the health department that should be reporting HIV information and recommend that field surveillance staff or STI/HIV prevention staff reviews point of contact information at least annually (optimally quarterly) for accuracy.

- Educate the point of contact on the expectations and reporting requirements
- Establish a protocol for reporting (electronic vs. non-electronic, frequency, required information)
- Establish automated electronic reporting mechanisms to minimize potential data reporting disruptions
Staffing & Training: Staffing Changes

**Current Situation:** Staff turnover affects the existing working relationships between the VHA and health departments.

**Recommendation (VHA):** Streamline the process of notifying health departments about:
- Current staff in charge of HIV lab and case reporting (including contact information and a back-up point of contact)
- Proactively inform health departments about staffing changes and provide contact information and backup point of contact for the new person in charge

**Current Situation:** Incoming staff members are not always aware of previously established routine reporting and/or an existing Standing Written Request Letter.

**Recommendation (VHA):** Share the information toolkit discussed in the next slide with the new staff to ensure that they are aware of any and all HIV reporting procedures and requirements at their facility.
Current Situation: There is no standard guidance that informs VHA facility staff on HIV-reporting best practices

Recommendation: Create information toolkit/pamphlet to ensure that all VHA staff involved in HIV care are aware of:

- VHA directives that encourage HIV case and laboratory reporting to the health department
- State-specific infectious disease reporting laws and regulations
- State-specific automated electronic reporting mechanisms
- [if signed] the Standing Written Request Letter that commits the VHA facility to report HIV cases to the health department
- Resources available to people living with HIV outside the VHA healthcare system (e.g., partner services programs that provide no-cost treatment and linkage to care for people living with HIV, programs that provide assistance with housing, medication assistance, other supportive services)
Current Situation: VHA staff may not be aware of how HIV data reported to the health department are used.

Recommendation: The CDC publishes an Annual HIV Surveillance Report, and many health departments also publish their own annual HIV surveillance summaries. In order to enhance VHA engagement, health departments should share these reports with VHA facilities to show the effect of their reporting efforts and demonstrate how and where the reported data have been used and that the VHA effort has not gone unnoticed.

- Emphasize the importance of the reporting and provide annual reports to show where and how the data are being used
- Utilize the annual reports to compare the number of cases in the health department system to those recorded at the VHA facility
Main Takeaways

Complete and accurate HIV surveillance depends on a collaborative relationship between health departments and the VHA facilities in their jurisdictions:

The VHA-health department relationship functions optimally when:

- Written commitment to facilitate reporting according to state laws and regulations is signed and in place
- Electronic and paper reporting forms are uncomplicated, yet serve their intended purpose
- Technologies that ensure efficient, automated, reporting and patient confidentiality are properly designed, deployed, and utilized
- Written policies and procedures that guide expectations of staff responsibilities and coordination across entities (e.g., STLT, VHA) are developed and implemented in training of existing staff and onboarding of new staff to ensure continuity of effort and compliance
Conclusions

The capability to reduce new HIV infections and ensure proper care for all people living with HIV in the U.S. depends on data gathering, tracking, and sharing across federal health services and public health entities.

Coordination between health departments and associated VHA facilities is a pivotal element of HIV surveillance in the Armed Forces Veteran population, which includes 18.4 million individuals (>7% of US population 18+ years) in 2022\textsuperscript{15}.

This toolkit offers health departments and VHA facilities suggestions for improving coordination, including modifications to information recording, data-sharing technologies, and workflow policies and procedures.

Leveraging existing electronic reporting mechanisms and standards for other infectious diseases may automate reporting and reduce burden on VHA facilities and STLTs.
19 health department representatives completed the assessment, reporting on 75 VHA facilities.

3 states reported on only one facility (FL, UT, VT), 11 states reported on 2-5 facilities (AR, CA, LA, MD, MA, MI, MN, NV, NC, ND, TN, WA), 4 states reported on 6-10 facilities (NE, NY, PA, WI).
Figure 2. Frequency with which the VHA facilities cooperate with health department follow-up investigations

Most facilities (n=47) cooperate with their health department always or most of the time. However, for 16% the health department replied that they are either not sure or the VHA facility never cooperates with follow-up investigations.
Insights from the 2022 Assessment on HIV Reporting

Figure 3. Percent of VHA facilities that report HIV patient care indicators to their health department

40% of VHA facilities (n=30) for which the health department representatives provided information do not report any HIV care indicators (such as CD4 tests, viral load tests, HIV sequencing tests or antiretroviral therapy medications) to their health department.
Among the facilities that do report HIV patient care indicators, CD4 and Viral Load test results are the most frequently reported. Reporting of these indicators depends on individual state infectious disease reporting laws and statutes.
Suggestions for improved HIV surveillance

- Consistent reporting methods at STLT level
- Simplified HIV reporting guidelines
- Onboarding for new VHA staff that emphasizes HIV reporting protocols and importance of infectious disease surveillance
- Improved familiarity with state-specific HIV reporting standards and requirements
- Open communication and good working relationships between health departments and VHA facilities
- Streamlined secure and confidential data sharing capabilities across facilities
- Development of a list of contacts at the VHA that is updated on a regular basis
- Highlight to the VHA the importance of sharing laboratory data to reduce follow up with people already in care
- Differentiate between people who are HIV-positive and people who are undergoing routine testing prior to a medical procedure.

Vital Statistics Consulting conducted 12 key informant interviews with STLT health department staff
Overview

Generally, CD4 tests are done not only for known HIV-positive patients, but also for all patients undergoing certain medical procedures (e.g., transplants). For both people who are HIV-negative and people who are HIV-positive undergoing antiretroviral therapy (ART), these results will show undetectable viral loads.

Current situation

Health departments investigate every HIV test result reported from commercial labs in standard electronic laboratory reporting format, including the CD4 diagnostic tests. When the diagnostic tests are not labeled as such, this creates unnecessary follow-up work (i.e., if they were labeled as diagnostic, the surveillance staff would not have to follow up on those).

Recommendations from Key Informants to Optimize Reporting of HIV Status

- **HIV-positive v. routine testing**: Indicate on the lab test slip (paper or electronic) whether the lab test was performed for diagnostic purposes (e.g., prior to a surgery or transplant) or for an HIV-positive patient
Success Stories

The following quotes highlight previous efforts to improve case reporting.

"One of the things that helped convince our VISN was that we were sending out DIS for data to care activities and finding out people were in care already. We also talked about the other services like HOPWA that vets may be entitled to." -- HIV Surveillance Coordinator

“We have a great relationship with the VA facility, and they are very supportive of anything our STLT health department needs.” -- HIV Surveillance Field Coordinator

“Using the CDC laboratory form helps to track not only volume of cases but also the facilities, which isolates any facility-level reporting issues.” -- HIV Surveillance Field Coordinator

“All regions [in my state] right now have positive relationships and everything is working well under the current practices.” -- HIV Surveillance Program Manager

“Individual clinicians in the VA are very eager to automate these reporting processes.” -- HIV Surveillance Epidemiologist

“The VA is responsive once the Department of Health reaches out to them to obtain patient information.” -- Chief, HIV Surveillance and Epidemiology
Consider the following steps for HIV case reporting:

- Read and understand relevant VHA Directives 1131 “Management of Infectious Diseases and Infection Prevention and Control Programs” and 1605.01 “Privacy and Release of Information” as well as state reporting laws.

- Generate and sign a reporting agreement (“written request letter” per VHA Directive 1605.01).

- Proactively report required HIV case information to the health department on the state-specific ACRF form or Adult HIV Confidential Case Report (ACRF) form.

- Electronically report HIV laboratory results to the health department from internal and external laboratory testing within established timeframes per individual state law requirements.

- Establish a designated VHA point of contact for all HIV case reporting-related inquiries and tasks.

- Create a standard set of written instructions on HIV-reporting best practices that can be used to train staff members.

- Use the Annual HIV Surveillance Report to compare and reconcile VHA and health department cases.
Resources


Please complete the VHA HIV Reporting Toolkit evaluation to provide end user feedback. The estimated completion time for this evaluation is 5-10 minutes. Individual responses will remain anonymous and confidential.

https://cste.co1.qualtrics.com/jfe/form/SV_2gJiUSgjRZbP4x0