



Ryan White Program Moving Forward

Data-Driven Approaches for Identifying and Engaging Out of Care and Undiagnosed People With HIV

Technical Expert Panel Executive Summary



The Health Resources and Services Administration HIV/AIDS Bureau, which administers the Ryan White HIV/AIDS Program (RWHAP), convened a Technical Expert Panel (TEP) in December 2025. The purpose of the TEP was to:

- Gather input from RWHAP recipients, federal partners, subject-matter experts, and stakeholders to better understand data-driven approaches to identifying and engaging people with HIV who are undiagnosed or out of care.
- Inform the development of key considerations for data-driven approaches to identifying and engaging people with HIV who are out of care or undiagnosed.

This summary discusses:

- Defining “out of care”
- Using data to identify out of care individuals
- Using data to inform outreach and engagement strategies
- Role of HRSA HAB in supporting out of care efforts by recipients



The Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) introduced Ryan White Program Moving Forward (RWP Moving Forward), a renewed vision for the Ryan White HIV/AIDS Program (RWHAP). RWP Moving Forward builds on the foundation of the RWHAP and innovative, low-barrier strategies from the Ending the HIV Epidemic in the U.S. (EHE) initiative. RWP Moving Forward calls on the HIV care and services community to continue to care for those clients in the RWHAP while expanding efforts to identify and engage individuals with HIV who are undiagnosed or out of care.

Identifying people with HIV who are unaware of their status and those diagnosed with HIV who are no longer engaged in care is critical to ending the HIV epidemic. If people with HIV are virally suppressed, they cannot sexually transmit HIV to others.

Defining “Out of Care”

There is no universally accepted definition of “out of care” for people with HIV. Across the RWHAP, recipients and subrecipients have developed various working definitions of “out of care” based on their program goals, available data sources, and local service delivery models. Recipients use these definitions to determine when a patient may be at risk of disengaging from care and when outreach, care navigation, or disease intervention staff should initiate re-engagement efforts. HRSA HAB encourages recipients to develop operational definitions that are appropriate for their local context and supported by available data systems.

Using Data to Identify Out of Care Individuals

Technical Expert Panel (TEP) participants provided feedback on various aspects of datasets and data use. The TEP emphasized that combining multiple data sources—including surveillance, clinical, pharmacy, and programmatic data—can improve accuracy when identifying people who are truly out of care and help ensure that outreach efforts are focused on individuals most in need of re-engagement.

Datasets

TEP participants discussed a variety of national, state, and local data sources that can be used to identify and characterize people with HIV who are out of care or undiagnosed.

Key Takeaways

Technical Expert Panel (TEP) participants identified several key considerations for using data to identify and engage people with HIV who are undiagnosed or out of care. Although Centers for Disease Control and Prevention HIV surveillance data are foundational, no single data source provides a complete picture. Combining multiple sources of data—including surveillance, clinical, pharmacy, programmatic, and other available data—can improve the accuracy and timeliness of identifying people who may benefit from outreach and re-engagement efforts.

- Identify and leverage data that are timely, accessible, and useful for informing outreach and re-engagement efforts.
- Develop collaborative relationships across federal, state, and local partners to improve data sharing and care coordination.
- Incorporate the client perspective to better understand barriers to care, tailor outreach efforts, and develop more client-centered services.
- Pair data with client-centered, low-barrier services to support successful re-engagement in care.

- **Centers for Disease Control and Prevention (CDC) HIV Surveillance Data.** The primary source of data for monitoring cases of HIV infection in the United States and the six U.S. territories/freely associated states. These data provide information on HIV diagnoses, deaths, and prevalence. Additional information collected includes routine reporting of HIV laboratory tests to the local, state, or territorial health department using a standard confidential case report form or via direct reporting from the laboratory. This information is then transmitted electronically to CDC without personal identifiers.
- **RWHAP Services Report (RSR).** An annual client-level data report that captures information on the individuals served, services provided, and health outcomes achieved through RWHAP-funded activities. Although the RSR is used primarily for program monitoring, quality improvement, accountability, and evaluation, participants noted that RSR data also can complement other data sources to better understand patterns of care engagement among RWHAP clients.
- **CDC Medical Monitoring Project (MMP).** Collects data on and provides information about the behaviors, clinical outcomes, quality of care, and barriers to care and viral suppression among people with diagnosed HIV in the United States.

TEP participants also discussed several additional data sources that may be available at the state or local level and can complement surveillance and RWHAP data. These additional data may provide insight into health care utilization and engagement and offer early indication that a patient may be at risk for falling out of care:

- Medicaid data (availability varies by state)
- Pharmacy data, including prescription fill and refill information
- Department of Veterans Affairs (VA) data for veterans receiving HIV care through the VA health system
- Electronic health record (EHR) data from health care providers and health systems
- Correctional health data from jails and prisons
- Data from community-based organizations and other service providers, including case management, housing, behavioral health, and substance use treatment programs

Data Collection

Collecting and analyzing data can strengthen recipients' ability to identify, prioritize, and engage people with HIV who are out of care. However, TEP participants noted that relevant data are often fragmented across surveillance systems, EHRs, pharmacies, Medicaid and other payers, correctional systems, community-based organizations, and other providers. As a result, no single data source provides a complete picture of an individual's engagement in care. Delays in data reporting, data entry, data sharing, and access can limit the timeliness and usefulness of information, making it more difficult for recipients to quickly identify, prioritize, and re-engage individuals who may be at risk of falling out of care. Participants noted that relying on a single data source can result in misclassification of patients (i.e., people who are classified as out of care but are still in care). Combining multiple data sources, when feasible, can improve the accuracy and actionability of out-of-care identification efforts.

TEP participants noted that data collection requires resources. These resources may be financial (e.g., paying for outside datasets) and/or relate to staff in terms of time, capacity, and expertise (for collection, analysis, and synthesis). Participants also discussed the challenges of accessing data from certain providers—such as substance use disorder treatment providers, correctional facilities, and housing providers—due to confidentiality requirements, differing data systems, and the temporary nature of some services.

Finally, participants emphasized the importance of collecting information that may support future re-engagement efforts. In addition to maintaining accurate demographic and contact information, recipients may consider collecting alternative contact methods—such as information for a trusted family member, partner, or other emergency contact—with the client's permission. Because phone numbers, addresses, and other contact information frequently change, having multiple ways to reach an individual can improve the success of future outreach and re-engagement activities.

Qualitative Data

While quantitative data can help identify people who may be out of care, qualitative data provide important context about the factors influencing engagement, retention, and re-engagement in care. TEP participants emphasized the importance of leveraging qualitative data to understand why someone is out of care and what motivates their engagement in care. This information cannot be fully captured through surveillance, clinical, or programmatic data alone. Qualitative data collected through needs assessments, outreach efforts, navigation services, and patient interactions can help identify barriers to care, such as housing instability, transportation challenges, mental health needs, substance use, stigma, competing priorities, or dissatisfaction with prior care experiences.

Some TEP participants described documenting information gathered during outreach and field investigations to better understand patterns and trends among people who are out of care and to inform future engagement strategies. Where feasible, these data can be captured during patient encounters in EHRs and provide insight into a patient's situation that may be useful for ensuring their engagement in care. Providers can ask patients about preferred methods of communication, trusted contacts, prior barriers to care, service needs, or provider preferences. Over time, these data can help providers better tailor outreach efforts, identify common challenges across populations, and develop more effective strategies for supporting re-engagement in care.

Data Sharing

Sharing data across health departments, RWHAP recipients and subrecipients, health care providers, pharmacies, Medicaid programs, health maintenance organizations (HMOs), correctional systems, and other partners can improve the accuracy and timeliness of identifying people who are out of care and support more coordinated outreach and re-engagement efforts. However, data sharing can be challenging. Common barriers include legal and confidentiality requirements, the establishment and maintenance of data-sharing and use agreements, organizational policies, and limited staff capacity.



TEP participants also emphasized that establishing and maintaining data sharing and use agreements can be time-intensive, and partnerships may be affected by staff turnover, leadership changes, competing priorities, or the expiration of existing agreements. Despite these challenges, several participants described successful collaboration among RWHAP recipients (Parts A–D), health departments, and other partners through well-established relationships, formal agreements, and clearly defined roles. Overall, the TEP emphasized that successful data sharing depends not only on formal agreements but also on strong partnerships, shared goals, and standardized processes that enable data to be exchanged in a timely, secure, and actionable manner.

Data Accuracy and Quality

Data quality plays a critical role in efforts to identify and re-engage people who are out of care. TEP participants noted that data systems often contain duplicate records, incomplete information, or outdated client information, which can make it difficult to determine whether an individual is truly out of care. Delays in reporting and reliance on manual data entry can further affect the accuracy and timeliness of information. TEP participants also highlighted challenges associated with linking and matching records across systems when client information differs among providers or over time. For example, individuals may use different names, contact information, demographic information, or other identifiers across health care and service settings. As people move among jurisdictions, providers, and systems of care, maintaining accurate and up-to-date records becomes increasingly important for identifying, locating, and engaging individuals who may be out of care.

Strategies for Re-engaging Clients

TEP participants identified a range of strategies for re-engaging people with HIV who are out of care. Successful approaches often combine data-informed identification efforts with low-barrier services, strong partnerships, and individualized outreach.

- **Identify champions.** Participants noted the importance of having staff who are committed to using data to support re-engagement activities and can help sustain partnerships, data-sharing efforts, and outreach activities. However, reliance on a single champion can create vulnerabilities when staff leave an organization. Embedding

these activities into routine operations and establishing succession plans can help ensure continuity.

- **Create low-barrier pathways back to care.** TEP participants emphasized that identifying someone who is out of care is only the first step. Re-engagement efforts are more successful when programs offer flexible and accessible services, such as walk-in appointments, same-day visits, transportation assistance, and other supports to reduce barriers to care. This includes flexible evening and weekend hours to allow access services during nontraditional clinic hours. Providers also can focus on creating a stigma-free environment where everyone feels welcome.
- **Solicit and act on feedback from patients.** Information collected through outreach efforts, case management, and client interactions can help programs better understand why individuals disengage from care and what support may be needed to facilitate their return. TEP participants highlighted the value of documenting barriers, service needs, and client preferences to support more personalized engagement strategies.
- **Use individualized outreach and peers to support entry into and retention in care.** Community health workers, navigators, outreach workers, and peers can play an important role in locating individuals, building trust, identifying barriers to care, and supporting re-engagement. Peers can help a newly diagnosed person navigate the process. When a person is engaged in care, a peer can be an ongoing source of support.
- **Case conferencing.** Regular case conferences (with both an internal team and external partner teams), reconciliation calls, and team huddles, as well as reviews of clients in danger of falling out of care, were among the most frequently cited strategies by TEP participants for identifying and re-engaging people who are out of care. Using available data, such as appointment no-shows or reschedules, as well as anecdotal information collected by the care team (e.g., changes in clients' lives, such as housing, employment, behavioral health issues), was also helpful.

- **Prioritize settings.** TEP participants identified several settings that can provide opportunities to identify and engage people who may be out of care, including:

- Jails
- Emergency departments
- Homeless shelters
- Substance use treatment and sober living houses
- Student health centers
- Community clinics

Role of HRSA HAB in Supporting Out of Care Efforts by Recipients

TEP participants identified several opportunities for HRSA HAB to support recipients and subrecipients in identifying and re-engaging people with HIV who are out of care:

- Develop guidance and resources that recipients and subrecipients can use to identify and prioritize people who are out of care. This includes guidance on measuring the effectiveness of outreach and re-engagement efforts, including process measures for outreach activities, successful contacts, and re-engagement outcomes.
- Develop guidance on how to use epidemiologic and diagnoses data to identify trends (e.g., which populations are disproportionately affected by poor retention in care efforts).

Conclusion

The TEP highlighted the critical role of data, partnerships, and low-barrier strategies in identifying and engaging people with HIV who are out of care. While data systems can help programs identify people who may need outreach services to bring them into care, TEP participants emphasized that no single data source is sufficient to accurately identify those who are out of care and that integrating multiple data sources and fostering meaningful collaboration across surveillance, clinical, and community-based systems is essential. The discussion also underscored that data alone are not enough. Successfully re-engaging people in care requires addressing the barriers that contribute to disengagement through flexible, low-barrier, and client-centered approaches that are responsive to individual needs and circumstances. Participants highlighted the importance of pairing actionable data with coordinated outreach, case conferencing, care navigation, and partnerships that support timely re-entry into care. By leveraging multiple data sources, strengthening cross-sector partnerships, and implementing person-centered re-engagement strategies, RWHAP recipients and subrecipients can enhance retention in care, improve health outcomes, reduce HIV transmission, and advance RWP Moving Forward.

