



# How States Use Medicaid and State Health Department Data to Improve Health Outcomes of People Living with HIV

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Sharing data between state health department HIV and Medicaid programs is integral to providing comprehensive and high-quality care to people living with HIV (PLWH). With consistent, well-coordinated care and daily access to antiretroviral therapy (ART), many PLWH can achieve virologic suppression.<sup>1</sup> PLWH who maintain virologic suppression have better health outcomes<sup>2</sup> and pose a significantly reduced risk of transmitting HIV to others.<sup>3</sup> However, sharing data across state agencies or departments can be complex due to:

- Federal and state laws that regulate certain types of information, including protected health information (PHI);
- A lack of consensus across state agencies about what data can or should be shared;
- Inadequate state information technology (IT) infrastructure; and
- Limited state resources.

This brief gives state officials an introduction to sharing and using data across Medicaid and state health department HIV programs to improve individual and population health outcomes. It explores three critical aspects of data sharing, including:

- Key components of a state's HIV data landscape;
- Data use and disclosure agreements between Medicaid and state health departments in general, and HIV programs in particular; and
- Data analyses and their use to inform policies and programs that help increase rates of virologic suppression.

This information is illustrated with lessons learned by the 19 states that participated in the HIV Health Improvement Affinity Group.

## Overview of State HIV and Medicaid Programs

The state divisions or agencies most likely to collect and share data related to Medicaid and Children's Health Insurance Program (CHIP) beneficiaries living with HIV are Medicaid and state public health department HIV programs, which oversee HIV surveillance, prevention, and treatment programs. State health department surveillance programs monitor and track HIV incidence, HIV prevalence, engagement in care, and HIV viral loads through collection of laboratory test results and other data.<sup>4,5</sup> State

### HIV Health Improvement Affinity Group

The [HIV Health Improvement Affinity Group](https://www.hiv.gov/federal-response/policies-issues/affinity) (HHIAG) provided support to 19 state Medicaid and public health department teams working to increase rates of sustained virologic suppression among Medicaid and Children's Health Insurance Program beneficiaries living with HIV.

HHIAG was a joint initiative between the Centers for Medicare & Medicaid Services, the U.S. Centers for Disease Control and Prevention, and the Health Resources and Services Administration, in collaboration with the Health and Human Services' Office of HIV/AIDS and Infectious Disease Policy, and in partnership with the National Academy for State Health Policy.

For more information: <https://www.hiv.gov/federal-response/policies-issues/affinity>

health department prevention programs focus on reducing new HIV infections through outreach and education that promote safer sexual and injection practices, as well as through increased access to testing, HIV partner services, and linkage to care.<sup>6</sup> Funding for state HIV surveillance and prevention programs is provided through cooperative agreements between the U.S. Centers for Disease Control and Prevention (CDC) and state and local health departments.<sup>7</sup>

State health departments also oversee the Ryan White HIV/AIDS Program (RWHAP). RWHAP provides treatment for PLWH who are low-income and uninsured, or underserved. The Health Resources and Services Administration (HRSA) awards RWHAP funding through grants and awards to states, eligible metropolitan areas, clinics, and community-based organizations. These funds pay for core medical and support services, such as outpatient ambulatory services, case management transportation, and behavioral health services for eligible PLWH.<sup>8</sup> The program is a payer of last resort, meaning program funds cannot be used for any item or service for which payment has been made, or “can reasonably be expected to be made,” by any other payer, including Medicaid. Every six months, grantees are required to assess clients for eligibility for other programs, including Medicaid, which could be responsible for the cost of payment of services provided.<sup>9</sup>

RWHAP also provides funds to states for their AIDS Drug Assistance Programs (ADAP).<sup>10</sup> ADAP is a state- and territory-administered program that provides U.S. Food and Drug Administration-approved medications to low-income PLWH who have limited or no health coverage from private insurance, Medicaid, or Medicare. ADAP provides assistance with health insurance premiums, co-pays, and deductibles.

Medicaid, jointly financed by federal and state governments, is the largest source of insurance coverage for people with HIV, and is estimated to cover more than 40 percent of PLWH who are engaged in medical care.<sup>11</sup> Covered benefits and service delivery for PLWH varies within each state’s Medicaid program. However, all state Medicaid programs provide coverage for:<sup>12</sup>

- Physician services
- Prescription drugs, including HIV drug therapies
- Inpatient and outpatient hospital services
- Laboratory services, including medically necessary HIV testing

For people enrolled in both Medicaid and RWHAP, the two programs can work in tandem to provide a comprehensive set of services and supports to PLWH. However, the interaction between these programs can be complex; eligibility criteria differs between them and PLWH may churn on and off one or both programs as their incomes fluctuate or they qualify for Social Security Disability Insurance. If PLWH temporarily lose eligibility for Medicaid, RWHAP may continue to provide support for Medicaid-covered services. For individuals who receive retroactive Medicaid eligibility status, RWHAP/ADAP may need to back-bill Medicaid for Medicaid-reimbursable services or medications.

## Understanding the State HIV Data Landscape

In order for PLWH to fully benefit from ART and achieve and maintain virologic suppression, they need to be aware that they are HIV positive, linked to and retained in regular HIV care, and receive and remain adherent to ART. The HIV Care Continuum illustrates the progression of PLWH through these clinical

stages, and offers state officials a useful starting point to evaluate how policies and programs impact retention in care and health outcomes for PLWH.<sup>13</sup>



Source: <https://hab.hrsa.gov/about-ryan-white-hiv-aids-program/hiv-care-continuum>.

Using the HIV Care Continuum as a framework, state policymakers and staff can:

- Determine the proportion of PLWH in their jurisdiction who are engaged in each stage of the HIV Care Continuum;
- Identify and assess where gaps exist in connecting PLWH to care; and
- Direct funding, policy and programmatic changes to better support PLWH.

States participating in the affinity group recognized that in order for care continuum modeling to be useful, comprehensive data, including clinical and health care utilization data, needed to be collected from both Medicaid and state health department HIV programs. While states can also integrate data from other state agencies serving PLWH (e.g., the Office of Minority Health, Department of Corrections, housing, or social service agencies), and from other data sources (e.g., all payer claims databases and health information exchanges), states generally focused on sharing data between Medicaid and state health department HIV programs as an important first step.

Medicaid and state health departments collect a wide variety of data relevant to PLWH. The following chart provides an overview of select data sources available to states for their PLWS population. It features key HIV-related data elements collected within each source, how those data elements can be used to construct an HIV Care Continuum for Medicaid and CHIP beneficiaries, and the limitations of each source.

Data System	Description	HIV-Related Data Elements	Data Usage and Limitations
<p><b>State Health Department HIV Surveillance Data</b><sup>14, 15, 16</sup></p> <p><i>Collected by the state health department.</i></p> <p><u>Federal reporting requirements:</u> All states, Washington, DC, and American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, the Republic of Palau, and the U.S. Virgin Islands collect HIV surveillance data and report de-identified data to the CDC's National HIV Surveillance System (NHSS) through the enhanced HIV/AIDS Reporting System (eHARS).</p> <p><u>Populations included:</u> This data source captures all persons diagnosed with HIV in the state/territory.</p>	<p>States collect surveillance data to monitor and analyze patterns in newly identified HIV diagnoses, HIV prevalence, clinical outcomes (e.g., CD4 and viral load), and morbidity and mortality rates. State health departments receive surveillance data from a variety of sources, including laboratories, health care providers, and viral statistic registries.</p>	<ul style="list-style-type: none"> <li>• Date of HIV diagnosis</li> <li>• PHI (e.g., date of birth)</li> <li>• Select demographic characteristics</li> <li>• Geographic location</li> <li>• Transmission category</li> <li>• Facilities and providers (diagnosing and care)</li> <li>• HIV-related laboratory test results</li> <li>• Clinical events</li> <li>• HIV testing, prophylaxis and treatment history</li> <li>• Birth history</li> <li>• Death and causes of death</li> <li>• Case duplication status (intra- and interstate)</li> </ul> <p>Some states have laws that allow both confidential and anonymous HIV testing so PHI may not be known until an HIV-positive individual accesses treatment services.</p>	<ul style="list-style-type: none"> <li>• Laboratory test results (e.g., CD4 and viral load) can provide insights into PLWH's engagement in care. Health department staff can target outreach to these individuals to help them find a health care provider or determine other barriers to achieving virologic suppression.</li> <li>• De-identified data submitted to CDC is analyzed to develop an annual surveillance report. States may use this information to better target resources to subpopulations or geographic areas of highest need.</li> </ul> <p>Limitations:</p> <ul style="list-style-type: none"> <li>• Not all states require laboratories to submit all CD4 and viral load test data. Data that is submitted to state health departments may be incomplete or have missing data elements.</li> </ul>
<p><b>Ryan White HIV/AIDS Program Service Report (RSR)</b><sup>17, 18</sup></p> <p><i>Collected by Ryan White HIV/AIDS Program (RWAHP) within state health departments.</i></p> <p><u>Federal reporting requirements:</u> All RWAHP-funded grant recipients (grantees) and sub-recipients (providers) must submit an RSR report, containing de-identified client level data, to HRSA each year.<sup>19</sup></p> <p><u>Populations included:</u> This data source captures all PLWH who are enrolled in RWAHP.</p>	<p>The RSR compiles individual client level data (a client report) annually for individuals who receive one or more RWHAP-funded services, as well as grantee and service provider information. Client reports generate a unique identifier for each RWHAP client based on name, date of birth, and other protected health information (PHI).</p>	<ul style="list-style-type: none"> <li>• Date of first ambulatory or outpatient visit with Ryan White provider</li> <li>• Date of birth</li> <li>• Date of death</li> <li>• Dates of ambulatory or outpatient HIV care</li> <li>• Dates and results of viral load testing</li> <li>• Year of HIV diagnosis</li> <li>• Prescribed date for ART</li> <li>• Indicators related to substance use and mental health, housing status, receipt of services related to housing, food, and transportation.</li> </ul>	<ul style="list-style-type: none"> <li>• Reports can help understand what core medical and support services PLWH are accessing (or not accessing) and assess quality of care.</li> <li>• Report captures individual-level demographic, clinical, and service utilization data for clients across providers.</li> </ul> <p>Limitations:</p> <ul style="list-style-type: none"> <li>• While many data elements in the RSR are similar to surveillance data noted earlier in the table, the RSR only reports health outcomes for PLWH who are eligible for and enrolled in RWAHP.</li> </ul>

<p><b>ADAP Data Report (ADR)<sup>20</sup></b></p> <p><i>Collected by Ryan White HIV/AIDS Programs within state health departments.</i></p> <p><u>Federal reporting requirements:</u> Ryan White HIV/AIDS Program Part B AIDS Drug Assistance Program (ADAP) must submit an ADR report, containing de-identified client level data to HRSA each year.<sup>21</sup></p> <p><u>Populations included:</u> This data source captures all PLWH who are enrolled in ADAP.</p>	<p>The ADR reports all ADAP-funded medication and insurance services that ADAP clients receive during the reporting period.</p>	<ul style="list-style-type: none"> <li>• Client demographics</li> <li>• Data on insurance and medication services</li> <li>• Clinical information (CD4 and viral load) for ADAP clients who receive medication services</li> </ul>	<ul style="list-style-type: none"> <li>• Number of ADAP clients who have received CD4 and viral load testing within the past year;</li> <li>• Proportion of ADAP clients who are receiving ART and are virally suppressed; and</li> <li>• Proportion of ADAP clients who are pregnant.</li> </ul> <p><u>Limitations:</u></p> <ul style="list-style-type: none"> <li>• Data limited only to ADAP clients receiving at least one ART medication paid for by ADAP.</li> </ul>
<p><b>Medicaid Management Information System (MMIS)<sup>22, 23</sup></b></p> <p><i>Collected by the state Medicaid agency.</i></p> <p><u>Federal reporting requirements:</u> All states and Washington, DC are required to submit Medicaid beneficiary and claims data to the Centers for Medicare &amp; Medicaid Services (CMS).</p> <p><u>Populations included:</u> This data source captures all state Medicaid and CHIP beneficiaries.</p>	<p>Each state operates a MMIS to process claims and collect data and information for Medicaid beneficiaries, such as demographic, eligibility, and utilization data.</p>	<ul style="list-style-type: none"> <li>• Demographic and monthly enrollment data for Medicaid beneficiaries</li> <li>• Paid claims files categorized by inpatient care, long-term care, prescription drug costs, other non-institutional services</li> <li>• Includes dates of service, providers, costs, and types of reimbursement</li> </ul>	<ul style="list-style-type: none"> <li>• Claims and encounter data, depending on the state, can be analyzed to identify Medicaid beneficiaries who have an HIV diagnosis and the services they are utilizing.</li> <li>• Service utilization patterns can help identify whether beneficiaries living with HIV are engaged in care, filling ART and other prescriptions, and seeking regular laboratory testing.</li> </ul> <p><u>Limitations:</u></p> <ul style="list-style-type: none"> <li>• Data, such as CD4, viral load, and HIV status, is not available through claims.</li> <li>• May not be a good indicator of the proportion of Medicaid beneficiaries who are PLWH due to fluctuating eligibility and lack of HIV claims that identify HIV status.</li> <li>• Up to a two-year time lag in data because of claims run-out periods.</li> </ul>

When successful, sharing data across state agencies can provide a more complete picture of the proportion of PLWH who are engaged at each stage of the HIV Care Continuum. This allows states to more accurately assess how well available clinical care and support services are addressing the needs of PLWH and identify what policy or program changes could have the greatest impact.

## Sharing Data Across Agencies: Establishing Data Disclosure and Data Use Agreements

Sharing the data described in the table above can be challenging, and while the confidentiality of health care information is critical, the complexity of federal and state health privacy laws can act as a barrier. Disclosure of PHI is regulated by a number of authorities:

- The [Health Information Portability and Accountability Act](#) (HIPAA) provides an overarching framework detailing how PHI may be shared. HIPAA provides significant flexibility to share PHI for the purposes of payment, treatment, and operations. The law also permits the sharing of a limited data set for research, health care operations, and public health purposes, as long as the transmittal is covered by a data use agreement (DUA) with certain safeguards. HIPAA also allows covered entities to disclose data to a public health authority, “for the purpose of preventing or controlling disease, injury, or disability.”<sup>24</sup>
- Confidentiality of substance use disorder patient records under [42 CFR Part 2](#) governs all records relating to the identity, diagnosis, prognosis, or treatment of any patient in a substance abuse program that is conducted, regulated, or directly or indirectly assisted by any department or agency of the United States.<sup>25</sup> The program must also “hold itself out as providing, and provide, substance use disorder diagnosis, treatment, or referral for treatment.”<sup>26</sup> In practical terms, 42 CFR part 2 can sometimes lead to suppression or exclusion of health records that contain any substance use disorder information, whether or not the entity meets the definition of “program.” Reviewing the scope of such suppression can be helpful to prevent overly broad application of the rule. 42 CFR part 2 does not prohibit drug and alcohol treatment programs from meeting state-mandated, communicable disease reporting.<sup>27</sup>
- State laws: Almost all states have statutes or regulations that address confidentiality of PHI, and often specifically the disclosure of HIV-related information. It is therefore important to consult with legal counsel or a state’s attorney general when examining the statutes that impact the sharing of data within a state.<sup>28</sup>

### **Protected Health Information Terms**

An **identifier** is one of 18 data elements, such as name, postal address, or Social Security number, that could disclose an individual’s identity, either alone or in conjunction with other information.

A **limited data set** excludes 16 out of 18 of these data elements, but is still considered PHI.

Source: 45 CFR § 164.514. Accessed November 14, 2017.

DUAs govern the sharing of limited data sets by covered entities, such as health plans, health care clearinghouses, or health care providers who electronically transmit any health information. Medicaid and state health departments are generally considered to be covered entities that perform qualifying functions, such as providing health insurance and/or providing services. DUAs establish how the limited data set may be used, and how it is protected.<sup>29</sup> Sharing HIV-related data across Medicaid and state health departments may require modifying or amending an existing DUA, or developing a new DUA between Medicaid and the state health department HIV programs.

## Key Considerations

State officials should consider the following when approaching the development or expansion of DUAs.

**Clearly articulate the questions that need to be answered.** Clearly defining the policy or program issue that needs to be addressed can be a helpful first step in the development of a DUA. State officials can then identify what data elements need to be shared to better understand and address the issue. Identifying how frequently to share data (e.g., annually, quarterly) should also be discussed.

- **Georgia's** existing DUA enabled the sharing of desired data elements between the Department of Community Health, which houses Medicaid, and the Department of Public Health, which houses HIV Epidemiology and the HIV Program. This interagency agreement had originally been put in place to improve public surveillance efforts.

**Be strategic when drafting or expanding DUAs.** When expanding or drafting a DUA, it can be helpful to consider not only what data is currently desired, but what data may need to be shared in the future. Consider implementing an overarching data agreement that would allow the exchange of a broader set of data. Although overarching DUAs may take more time to draft, states participating in the affinity group found them helpful when accessing data that had not been explicitly anticipated or increasing how frequently data is shared without having to renegotiate a DUA. This can save states significant time, as a new DUA will not need to be put in place and it provides maximum flexibility within the existing DUA.

- The **California** Health and Human Services Agency has an overarching DUA in place for data exchange between departments, which includes the Department of Health Care Services (Medicaid) and the Department of Public Health (Office of AIDS). The departments developed a business use case that specifically outlines the parameters of sharing HIV-related data. The state reports that the overarching DUA has streamlined the process of sharing data for specific projects<sup>30</sup>

**Clearly define and understand the legal parameters of what data can be shared and how it can be used.** Due to the interplay of state and federal rules around data sharing, states found developing or amending DUAs is not necessarily a one-size-fits-all process. Engaging legal counsel early on can be helpful. Additionally, having Medicaid or state health department staff participate in the state's Institutional Review Board (IRB) may also help build a better understanding of interagency data sharing. Lastly, cataloging data-sharing activities within a state can be a useful exercise to understand what types of DUAs are already in place and the types of data already being shared, so that existing agreements and processes can be leveraged as appropriate.

- A Division of HIV and STD Programs staff member in **Michigan's** Department of Health and Human Services also serves on the state's multi-agency IRB committee. Members of the Michigan affinity group team reported this has been invaluable in developing staff capacity to understand the complexities of data sharing under state and federal regulations.

**Establish and maintain partnerships across agencies.** The more data that states have available to them, the more accurate a picture of exactly where gaps in health care exist for PLWH. Building partnerships with agencies that do not currently exchange data can help states target resources and create a more accurate care continuum. States participating in the affinity group noted the importance of formalizing relationships and instituting regular collaboration as a way to strengthen shared programmatic goals and reinforce the importance of sharing data. For example, establishing regular coordination between Medicaid directors and state AIDS directors ensures that both programs understand the scope of benefits necessary to meet the comprehensive needs of PLWH, and each agency's role in providing

them. Similarly, states with RWHAP Part A grants can leverage Medicaid representation on RWHAP Part A Planning Councils to help foster relationships.

- Through their participation in the HIV Affinity Group, **Alaska** Department of Health and Social Services officials were able to meet and establish a working relationship with the state's Medicaid Director for the first time.
- In **Massachusetts**, the Department of Public Health and the state's Medicaid and CHIP program, MassHealth, formalized interagency communication processes. This has resulted in more frequent communication between the two agencies.

## Analyzing and Using Data to Inform Policy and Programs

Accurate and complete data can help states monitor and address gaps in care for PLWH. For example, states can use cross-agency data sets to:

- Identify PLWH who were not identified by either Medicaid or HIV surveillance and RWHAP;
- Identify PLWH who are/not linked to or engaged in regular care;
- Identify PLWH who are/not filling their prescriptions for ARTs;
- Identify PLWH who are/not virally suppressed;
- Identify geographic areas with resident PLWH with high service needs; and
- Identify disparities among underserved populations and racial and ethnic minorities.

With a more complete data picture, states can make informed policy decisions about how and where to target existing services (such as care coordination, community health workers) and to focus additional resources to achieve better outcomes and experiences for PLWH.

### Key Considerations

**Understand a state's IT infrastructure and capacity.** A strong IT infrastructure is central to a state's ability to share and analyze comprehensive data sets across state agencies. State officials may begin by assessing systems required for a strong IT infrastructure that include record linkage software, computers with the required speed, memory, and hard drive capacity for large data sets, and staff with knowledge of both data analytics and familiarity with Ryan White HIV/AIDS and Medicaid programs.<sup>31</sup>

- **Louisiana** has leveraged federal Health Information Technology for Economic and Clinical Health (HITECH) Act<sup>32</sup> funds to support the state's Office of Public Health to enhance its surveillance and lab management systems so that they comply with "Meaningful use" requirements and are better equipped to collect and subsequently share data.<sup>33</sup>

**Identify the population.** DUAs can allow Medicaid agencies to share claims from its entire population, or they can limit data sharing to claims from individuals who are likely to be PLWH. If states want data on only PLWH, they need to structure data query parameters in ways that can effectively identify HIV-positive individuals.

- **Maryland** is in the process of developing a DUA between the Public Health Services department and the Office of Health Care Financing (Medicaid) within the Department of Health so that HIV program staff will be able to access Medicaid claims data. When the DUA was developed, Maryland created a list of claims-based codes that could indicate if a beneficiary is HIV positive, received HIV testing, or receiving PrEP. Once the DUA is in place, these codes will be used by data analytics staff to identify and describe beneficiaries who meet that criteria. Maryland also plans to create data files of HIV-positive beneficiaries for future analysis of claims utilization.

**Anticipate data-matching challenges.** Data matching compares variables between data sources, such as health department HIV surveillance and Medicaid claims data. Most affinity group states noted challenges once they began the data-matching process, such as when data is not reported to the state in a timely or complete manner or when data elements (e.g., name, date of birth) are not included or reported in the same way across data sources. States may also need to refine the algorithm they use to generate “matches” across data sets over time. This can help analyses to more accurately identify HIV-positive Medicaid beneficiaries, and reduce the number of Medicaid beneficiaries incorrectly identified as being HIV positive or HIV negative.<sup>34</sup>

**Communicate data in ways that are accessible to stakeholders.** To truly improve outcomes and inform policymaking, data must be presented in a way that clearly and concisely displays the results of the analysis to appropriate stakeholders. Tailored approaches to data sharing have been shown to improve provider-reported capacity, peer learning, and support for PLWH.<sup>35</sup> Differing provider, payer, and state vocabularies are a perennial challenge to effective communication, which can impact the implementation of successful policy solutions. Presentation of data should be tailored specifically for the intended audience in order to build a common understanding and foster effective communication. The following three recommendations can help tailor information to the targeted audience:<sup>36</sup>

1. **Determine the design of the chart or graph that will be used to display the data**, keeping in mind the audience’s level of familiarity with data analysis;
2. **Simplify visual elements**, think intentionally about color to highlight important information, remove unnecessary elements such as borders, tick marks, shadows, or outlines, and directly label the graph to allow the audience to focus on the important details without wading through unnecessary visual elements; and
3. **Emphasize the story** by using strategic text, an impactful and active title, and color to engage the audience.

Regular analysis and clear communication can help state officials effectively evaluate HIV-related policies and programs and communicate opportunities for improvement to their peers, as well as other stakeholders, in order to ultimately improve rates of virologic suppression in PLWH.

## Conclusion

Strong cross-agency collaboration and partnership is critical to providing comprehensive, high-quality care to PLWH in effort to increase rates of virologic suppression. Sharing and analyzing multiple data sets can help state officials make more informed policy and programmatic decisions, and target limited resources to where they can have the greatest impact on outcomes for PLWH.

In the HIV Health Improvement Affinity Group, 19 states worked to enhance their use of data to drive increases in virologic suppression rates. While each state worked on a unique quality improvement project, their work generated notable and promising practices and lessons learned:

- Develop and formalize collaborative relationships with other state agencies;
- Understand what data is available to help inform policy decisions;
- Work closely with legal counsel to develop DUAs that can meet long-term data needs;
- Be ready to troubleshoot issues that may arise when analyzing the data; and
- Once compiled, present data effectively for key audiences.

## Endnotes

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