










# HIV Health Improvement Affinity Group

2019  
EVALUATION  
REPORT



# Table of Contents

<b>INTRODUCTION</b>	<b>03</b>
<b>RESULTS</b>	<b>04</b>
<b>STATE AGENCIES</b>	<b>04</b>
 Road to the Affinity Group	04
 Collaboration	05
 Knowledge	09
 Outcomes	09
 Lessons learned	13
<b>FEDERAL AGENCIES</b>	<b>17</b>
 Road to the Affinity Group	17
 Collaboration	17
 Knowledge	18
 Lessons learned	20
<b>DISCUSSION</b>	<b>23</b>
References	25
Acknowledgements	25
<b>APPENDICES</b>	<b>26</b>
Appendix 1: Program Description	26
Appendix 2: Evaluation Methods	29

## Introduction

Of the estimated 1.1 million Americans living with HIV in 2015, 85% were aware of their HIV infection, and about half (49%) were virally suppressed (1). Viral suppression is not only crucial to ensure optimal HIV health outcomes among people living with diagnosed HIV (PLWH), but also to prevent further transmission of the virus (2, 3).

Medicaid is the single largest source of care for PLWH (4). The Federal National HIV/AIDS Strategy: Updated to 2020 Federal Action Plan (5) called for the Centers for Disease Control and Prevention (CDC), the Centers for Medicare & Medicaid Services (CMS) and the Health Resources and Services Administration (HRSA) to form an HIV affinity group. The goal of the HIV Affinity Group was to develop and implement state-specific plans that would increase viral suppression and improve health outcomes for PLWH enrolled in Medicaid through collaborations between state public health departments and state Medicaid agencies. In some states public health and Medicaid operate under one organization while in others these programs are separate (6).

The HIV Affinity Group was the first affinity group to be co-led and co-managed by multiple federal agencies (CDC, CMS, and HRSA), with support from the HHS Office of HIV/AIDS and Infectious Disease Policy (OHAIDP), and in partnership with the [National Academy of State Health Policy \(NASHP\)](#). It is also the first affinity group with a specific goal to increase collaborations between state public health departments and state Medicaid agencies. The HIV Affinity Group was launched in October 2016 for a one-year period with participation from 19 states.<sup>1</sup> These 19 states accounted for about 50% of new HIV diagnoses in 2016 and 54% of PLWH at the end of 2015 in the United States.

An evaluation was conducted to assess the processes and short-term outcomes associated with the HIV Affinity Group, including whether the affinity group model facilitated new or enhanced processes or structures that helped participants achieve the objectives outlined in their state action plans. The evaluation also captured lessons learned by state participants and federal partners. The primary audience for this evaluation report are the state public health departments and state Medicaid agencies that participated in the HIV Affinity Group, the federal agencies involved in the management and support of the HIV Affinity Group, and other states and federal agencies (e.g., the Department of Housing and Urban Department and the Substance Abuse and Mental Health Administration) that may be interested in cross-programmatic collaboration.

---

<sup>1</sup> Alaska, California, Connecticut, Georgia, Illinois, Iowa, Louisiana, Maryland, Massachusetts, Michigan, Mississippi, Nevada, New Hampshire, New York, North Carolina, Rhode Island, Virginia, Washington, and Wisconsin

# Results

## STATE AGENCIES

The information presented in this section reflects state Medicaid agency and state public health department HIV Affinity Group participant responses to questions about motivation to participate, benefits received, outcomes, and lessons learned.



### Road to the Affinity Group – Motivation to Participate

Respondents from both state Medicaid agencies and state public health departments wanted to improve partnership with the other agency to eliminate silos and ensure continuity of care for PLWH in their states.

“I think it was a very important thing to do [. . .] to get collaborations going together in a direction that improves patient care [. . .] and be able to work with Medicaid. I found this a very rewarding experience. Our director was very open to participating and gave us the support that we needed.”

- State Public Health Department respondent

While some states already had existing cross-agency relationships, others did not collaborate at all. The HIV Affinity Group was seen as a platform to develop ideas into realistic, substantive projects.

“It's something that we've sort of bandied about and talked about and this seemed like a good opportunity to really take a closer look at that. As you know, all states have many different priorities, things that take time, so this really gave us an opportunity to spend some time focusing [. . .] and understanding the data sets that [our public health department] may be collecting and there's just some sort of missing holes in both of our respective datasets that could be filled by collaborating more closely with each other.”

- Medicaid Agency respondent

State public health department respondents were particularly interested in exploring the Medicaid data to calculate viral suppression rates among Medicaid beneficiaries, to find gaps in care, and, in some cases, monitor pre-exposure prophylaxis (PrEP) use. State Medicaid respondents were interested in improving clinical and nonclinical management for persons living with HIV. One respondent reported that prior to the HIV Affinity Group, their state Medicaid agency housed multiple quality improvement programs to improve prevention and care for various health conditions, but the respondent was not aware of any specifically focused on HIV. The prospect of peer-to-peer learning, especially from the states that already had implemented some innovations in data sharing and quality improvement initiatives, appealed to both state health department and state Medicaid agency respondents.



## Collaboration

The process of jointly developing state action plans spurred collaboration between state Medicaid/CHIP and state public health department staff.

These state action plans emphasized the following:

- Exchanging and using public health and Medicaid data to monitor care quality and improve health outcomes among beneficiaries living with HIV;
- Better coordinating delivery of services to improve effectiveness and efficiency; and
- Building partnerships between public health and Medicaid agencies that are structural as well as personal.

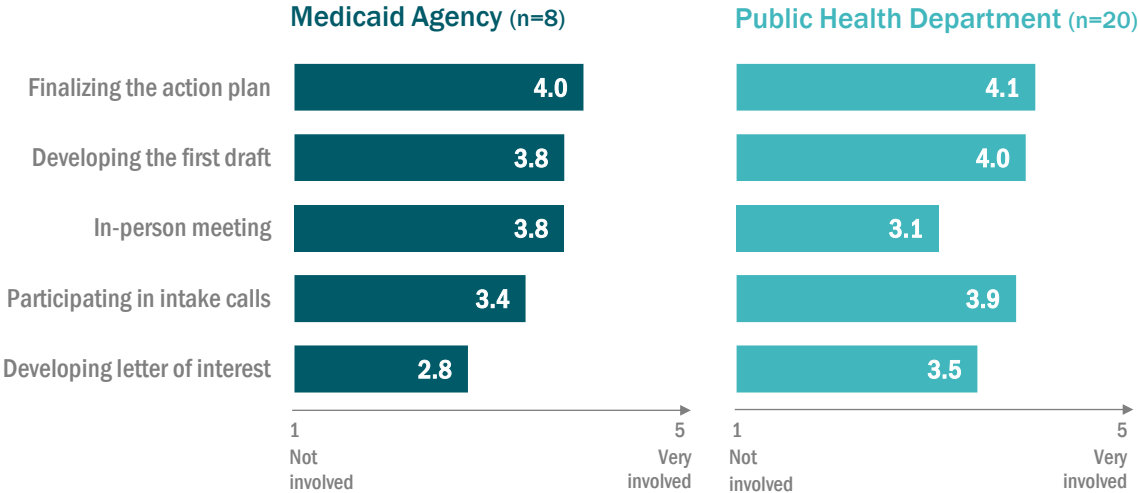
Respondents were asked about their level of involvement in the steps associated with developing their state action plans (see below).

### State Action Plan Development



Both groups of respondents were about equally involved in developing and finalizing the action plans. State public health department respondents were more involved in developing the letter of interest and participating in intake calls than state Medicaid agency respondents, while state Medicaid agency respondents were more involved in the December in-person meeting.

The average rating for **State Medicaid Agency** and **State Public Health Department involvement** in state action plan activities.



Overall, approximately half of respondents reported forming *new* collaborative relationships as a result of the HIV Affinity Group. There was only slight variation by agency (50% of state Medicaid agency respondents and 44% of state public health department respondents).

“Prior to this project, Medicaid and the Ryan White Part B Program had no interactions. We now email and communicate freely and discuss project updates. I have been able to reach out to my Medicaid partner to discuss topics beyond this project and have received assistance and guidance from my Medicaid partner.”

- State Public Health Department respondent

When asked to describe their relationships before joining the HIV Affinity Group (adapted from Frey et.al. (7) – see sidebar), on a scale of 1-5 state Medicaid respondents reported stronger relationships with state public health departments (3.1) than the state public health departments reported with state Medicaid agencies (2.7).

Respondents from both state Medicaid agencies and state public health departments reported that their relationship improved by the conclusion of the HIV Affinity Group (state Medicaid: 3.1 to 3.8; state public health departments: 2.7 to 3.3), and anticipated even further partnership in the future (state Medicaid: 4.1; state public health departments: 3.6).

### Levels of Collaboration

**1 - No Interaction**

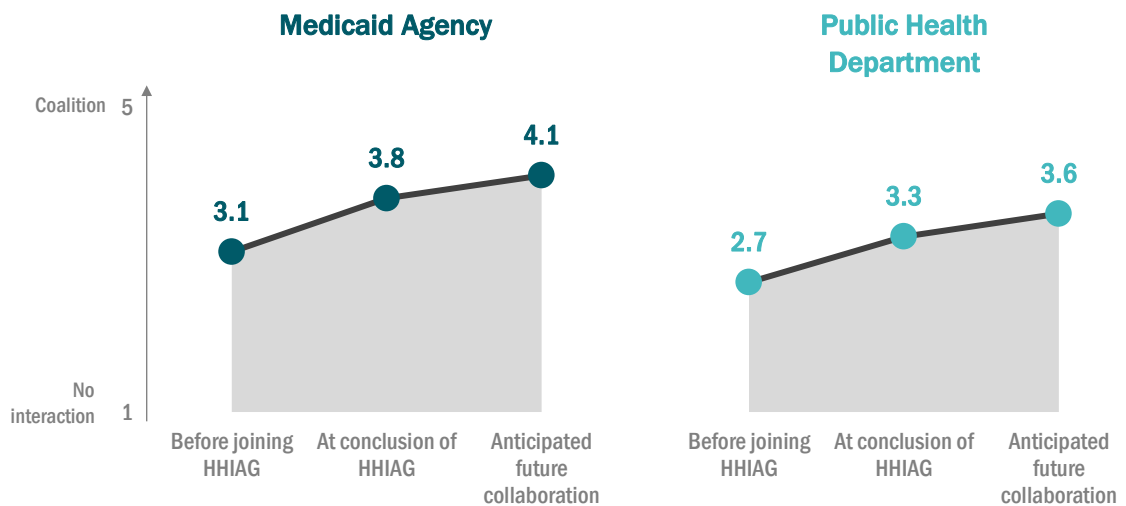
**2 - Networking:** Aware of organization; loosely defined roles; little communication; decisions made independently.

**3 - Cooperation:** Provide data to each other; somewhat defined roles; formal communication; decisions made independently.

**4 - Coordination:** Share data, defined roles; frequent communication; some shared decision making.

**5 - Coalition:** Share ideas; frequent & prioritized communication; shared decision making.

The average rating for **State Medicaid Agency** and **State Public Health Department** relationship with collaborative partners over time.



New relationships were formed between Medicaid, health department and managed care organization within the same state, which was the one of the main goals of the HIV Affinity Group. However, the experience also strengthened relationships between participating states as well as between states and federal partners. Such relationships were seen as opportunities for additional learning, assistance, and future partnership. In one example, participants from one state visited another state to learn about their best practices. The interviewee added:

“We have shared our data sharing agreement with other states and our methods for matching data and calculating viral suppression. We have also learned a lot about data analysis and Managed Care Organizations (MCOs) interventions from other states.”

- State Public Health Department respondent

One HIV Affinity Group participant believed that they could seek additional technical assistance from federal contacts they identified through the HIV Affinity Group.

“If things fall apart with the agreement, I know whom to contact nationally to help us with more technical assistance.”

- State Public Health Department respondent

In addition to new relationships, respondents reported gaining inspiration and confidence from their peer states' successes. It was also helpful to see other states navigate similar challenges.

“I think some of the examples we see from other jurisdictions allows us to reference those and say "look what so and so is doing. Look what Louisiana is doing, look what Rhode Island is doing" It normalizes some of the changes that we're proposing which on their surface – look, I wouldn't say exactly groundbreaking but certainly we're moving the system beyond where the historic limits that we have been operating under.”

- State Public Health Department respondent





## Knowledge

Respondents reported gaining new information about, and understanding of, the following:

- Organizational culture, priorities, and policies of the partner agency;
- HIV prevention programs and funding at the federal level;
- Strengths and limitations of the different data sets;
- Data interpretation (e.g., HIV medication carve outs, ICD 10 data codes, NDC drug codes) and value sets to help develop and validate data specifications.
- Provider engagement strategies and quality improvement initiatives.

Half of state Medicaid respondents reported that they acquired new skills or knowledge, compared with 65% of state public health department respondents. More than 60% of respondents reported that they gained access to new documents/information, regardless of affiliation.

### Knowledge and information acquisition, by respondent affiliation and learning community

Acquire New Skills or Knowledge		
Respondent Affiliation	Yes	No
State Medicaid Agency	50%	50%
State Public Health Department	65%	35%
Gain Access to New Documents/Information		
Respondent Affiliation	Yes	No
State Medicaid Agency	67%	33%
State Public Health Department	61%	39%



## Outcomes

### Data sharing agreements

At the end of the one year period, 13 (68%) of the 19 states participating in the HIV Affinity Group had established or refined their data sharing agreements between state Medicaid agencies and state public health departments.

Forming data sharing agreements between state Medicaid agencies and state public health departments was an important first step in many of the state action plans. While some states refined already existing data sharing agreements, others started from scratch. This process took longer than anticipated for most respondents, which was partially due to organizational bureaucracy and time needed to coordinate meetings with the appropriate people.

Other respondents reported that time was needed to achieve a shared vision and reach clarity on how the data would be used. As one respondent noted:

“It’s much easier to amend an outstanding data use agreement and once everybody in these organizations have some familiarity with it, it’s a little easier to make changes. [. . .] We will still have to go through all the rounds of revisions and signatures but I think it’s a matter of blazing the trail and kind of paying up front. But I think we can continue to work on that and we should expect to see changes happen more quickly in the future.”

- State Public Health Department respondent

### Data matching

Of the 13 states that established or refined their cross-agency data sharing agreement, 92% (n=12) successfully matched the data or streamlined the data matching process.

States matched Medicaid administrative data with HIV surveillance data and, in some cases, Ryan White HIV/AIDS Program data to generate an HIV care continuum (8) based on population characteristics or managed care plans. Generally, state public health departments gained access to Medicaid data, but some bi-directional data sharing occurred.

#### HIV Care Continuum (8)

The series of stages of HIV medical care that a person with HIV goes through from initial diagnosis through to achieving the goal of viral suppression.

Respondents had difficulties learning how to match the different data sets. For example, deciding what codes to use to effectively match HIV surveillance data with managed care organizations (MCO) service utilization data was an iterative process. States needed time to build technical knowledge of the variables in each data set to assess their usefulness and ability to generate an HIV care continuum.

“Developing the coding net was a challenge for us. Neither of our departments Medicaid or public health had really technical experience with knowing what the diagnosis ICD 9/10 codes would be for someone with an HIV diagnosis or what procedures to look for to indicate viral load going up down whatever it might be [. . .] eventually we were able to have one of the people in public health to go through and decide what would be most appropriate to include in our coding net but that was a time consuming piece. Our concern is that we want to be sure that we're all talking about the same thing when we are using different definitions”

- Medicaid Agency respondent

Ensuring the accuracy and completeness of the combined data set is important. Gaps in data quality could compromise the validity, value, and efficiency of actions based on those data (e.g., tying results to incentives or using data to guide data to care outreach). One respondent shared:

“We don't have the whole data set that we are drawing conclusions from because some folks in the HIV database were not accurately matched with the folks in the Medicaid data warehouse. So we lost people in the measurement of 'are you virally suppressed or not' and so it compromises the accuracy of our data, which really compromises our ability to tell health plans that they have to do something about a rate that they can then come back and say 'well that's not that's not my whole performance you can't tie money to my performance in a rate that's not accurate.' So the more accurate we can make our measurement the more likely if and when we need to, we can put this into an incentive type structure for improvement or at least start drawing baseline [. . .] But with this matching issue, it puts this on a delayed track to really get the ability to start doing something like that.”

- Medicaid Agency respondent

### Generating viral suppression rates

Of the 12 states that successfully matched the data or streamlined the data matching process, 67% (n=8) generated an HIV care continuum for state Medicaid beneficiaries, including estimating viral suppression rates, and identified targets for performance improvement. For example, one state measured viral suppression among Medicaid beneficiaries living with HIV and also examined viral suppression by managed care plan to generate reports on an annual basis. Preliminary results for this state showed that outcomes looked similar between managed care and non-managed care beneficiaries. The participant added:

“This type of work is going to keep going, it's iterative and we are going to keep at it.”

- State Public Health Department respondent

Another state streamlined their data generation and analytic processes to the point where they could provide viral suppression results to managed care plans on a quarterly basis. All plans within the state had a higher percentage of PLWH in care than the overall state percentage and more than half of plans exceeded the state's viral suppression rate of 82%.

### Quality improvement initiatives and policy changes

Of the eight states that generated an HIV care continuum for state Medicaid beneficiaries and identified targets for performance improvement, 63% (n=6) began quality improvement initiatives during the project period; these included informing MCOs and medical providers about the importance of measuring the HIV care continuum, the barriers for PLWH linking to care and staying engaged in care, and the support programs available for PLWH. For example, public health and Medicaid

participants in one state developed customized fact sheets for each Medicaid plan that presented data to show disparities in viral suppression by race, sex, and geography. Another state, with considerable experience in this area, formed a “mini” HIV affinity group for statewide Medicaid managed care plans to identify and share best practices to increase viral suppression through targeted outreach, care coordination, and clinical services. Although one state was not able to exchange data in the one-year project period, their cross-agency collaborations resulted in administrative and policy changes. In this state, newly contracted MCOs are now mandated to share data to support quality improvement initiatives.

More information on state specific stories is available at the NASHP [“Toolkit: State Strategies to Improve Health Outcomes for People Living with HIV”](#) website.

**Sustainability of accomplishments**

Nearly all respondents reported that they were “somewhat likely” or “very likely” to sustain their accomplishments as a result of participating in the HIV Affinity Group. However, respondents from state public health departments were, on a whole, more confident (i.e., majority of them answered “very likely”, while the majority of Medicaid agency respondents answered “somewhat likely”). Respondents did not report factors that influenced their likelihood of sustaining HIV Affinity Group accomplishments.

**Likelihood of Sustaining the HIV Affinity Group Accomplishments, by respondent affiliation**

Respondent Affiliation				
	Very Likely	Somewhat Likely	Somewhat not Likely	Not likely
State Medicaid Agency	17%	83%	0%	0%
State Public Health Department	69%	25%	6%	0%



## Lessons learned

### Federal & NASHP support

Respondents appreciated that federal partners and NASHP took a middle ground between imposing outcomes and having no expectations. NASHP and federal partners were there to provide technical support, but states led the way towards identifying and implementing policy and program changes to improve viral suppression among Medicaid beneficiaries living with HIV.

“There is no mandate for this. We are not going to fail. We may succeed but we are going to attempt to do something that increases care for patients and it's our own goal with Medicaid and our own objectives and I think that I had to be really clear with the staff this wasn't the Affinity Group's objectives, it was our objectives and we were going to work towards it.

- State Public Health Department respondent

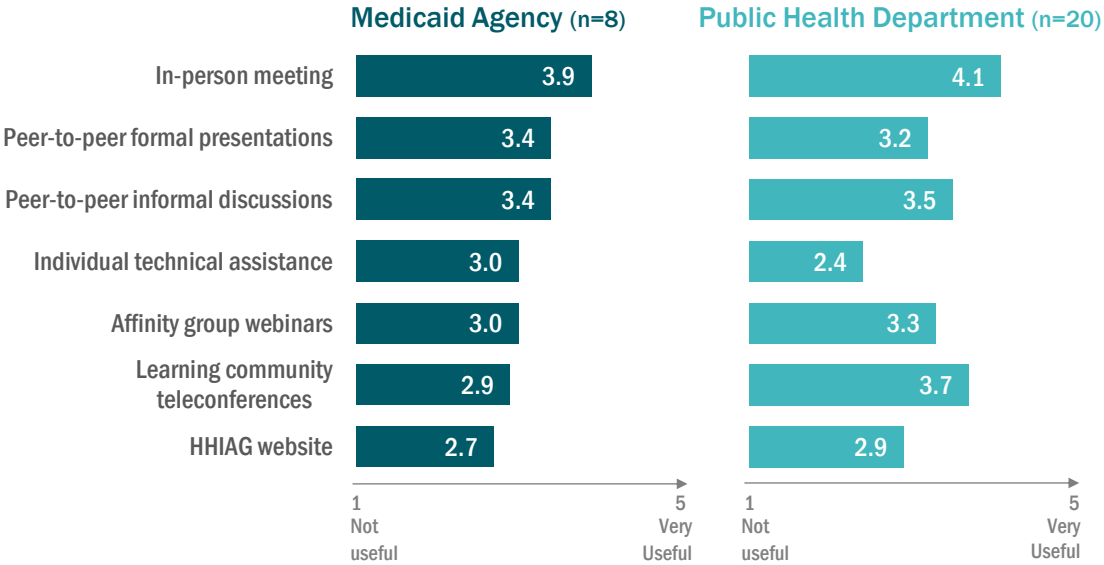
Although there was no expectation for states to reach every objective or limit their collaborative relationship to the objectives included in their plans, states indicated that having deadlines and regular monitoring of the progress created a structure that kept them on track with their goals.

“I do think that we tend to (at the state) to make progress when we're in a program like this that's sort of pushing you onward, and making you set goals, and meet again, and things like that otherwise, sometimes they get pushed to the back burner if you don't have that impetus.”

- State Public Health Department respondent

Of the different types of activities and resources offered by federal partners and NASHP, respondents found peer-to-peer exchange most useful. Peer-to-peer exchanges took place during the in-person meetings and the learning community teleconferences where states shared their successes, barriers, and future plans. However, there were differences between state public health department participants and Medicaid participants in terms of which activities they preferred. State public health staff favored learning community calls more than Medicaid participants, while Medicaid participants found webinars and peer-to-peer formal presentations slightly more useful than state public health department participants.

**State Medicaid Agency** and **State public health department** ratings on the **utility** of the HIV affinity group activities in implementing state action plans.



**Agency buy-in**

The pace at which states implemented their action plan was often limited by budget and staffing constraints. Participation in HIV Affinity Group activities added workload to an already taxed workforce in both agencies, without any additional funding. While respondents saw the value in the work of the HIV Affinity Group, others in their agencies did not always support colleagues spending agency time and resources on HIV Affinity Group activities. Support for the HIV Affinity Group from CDC, CMS, HRSA, OHAIDP, and NASHP gave credibility to the HIV Affinity Group and helped participants to justify time and resource investment.

“I think one of the benefits of having such a robust group - of different CDC and the policy group and everyone involved with CMS - is it brought some credibility to the project to our state so I could attend the meetings, and I could participate because CMS is such a large player in every state for services doing something in collaboration with CMS really brought some credibility to this project that allowed me to participate.”

- State Public Health Department respondent

As the work progressed, one HIV Affinity Group respondent noted increased buy-in from others in their agency who came to realize the value of matching Medicaid claims data and HIV surveillance data. Agency staff understood that information about viral suppression among Medicaid beneficiaries living with HIV would help them target limited resources to PLWH who were not regularly seeking HIV care or have other barriers to care.

“*[My staff] did not see the benefit of doing it. But as we went through the process and reviewed the data, they came around and said: yeah this is important [. . .] We are finding out some information we didn't know before.*”

- *State Public Health Department respondent*

Agency buy-in was also sometimes affected by different interpretations of, and approaches to, perceived roadblocks. For example, different interpretations of the Health Insurance Portability and Accountability Act (HIPAA) by state public health department and state Medicaid officials sometimes emerged as a barrier to data sharing. Ultimately, most states were able to resolve these differences and move forward; those that couldn't (at least within the project period) remained hopeful that the two agencies would eventually reach a data sharing agreement.

### **Cross-agency differences**

Respondents emphasized the need to both acknowledge differences between Medicaid and public health (e.g., culture, policies and priorities) and set appropriate shared expectations early in the project. Understanding organizational differences and agreeing on shared project objectives may take time, but it is an important part of building a strong partnership.

“*Agencies operate differently and so it was kind of a translation type exercise to work together with HIV to be able to communicate to the Medicaid Health Plans in a way that they will digest information and seek to do something action oriented around it. I think it was a productive partnership and we are really trying to work together to whittle down the presentations to a way that the plans would understand, see what they ask was, and understand what the state was asking of them.*”

- *Medicaid Agency respondent*

One respondent noted that he was surprised to discover that some data sharing processes already existed between two agencies. To sustain their accomplishments, he advised others to expand on existing relationships whenever possible, and to invest time in formalizing new or expanded relationships.

### Suggestions for next steps

Respondents generally wanted the HIV Affinity Group to continue beyond one year. Were the HIV Affinity Group extended, respondents recommended the following adjustments:

- Expanding state membership to other agencies with the state;
- Directing more time and resources to fostering in-depth discussions around common challenges with which states were struggling; and streamlining group communications (e.g., fewer emails, simplify access to website).



## FEDERAL AGENCIES

The information presented in this section reflects federal participant responses to questions about motivation to participate in the HIV Affinity Group, specific benefits received, and lessons learned as a result of participation in the HIV Affinity Group.



### Road to the Affinity Group – Motivation to Participate

Federal respondents provided several reasons for participating in the HIV Affinity Group beginning with the federal implementation plan for NHAS 2020 (5) that specifically instructed CMS, CDC, and HRSA to form an HIV Affinity Group. However, there were other reasons mentioned including partnering with public health organizations around quality improvement efforts for PLWH was relevant and timely due to the passage of the Affordable Care Act in 2010, beginning in 2014 Medicaid programs in expansion states experiencing a large influx of beneficiaries in need of HIV services, and the opportunity to strengthen ties among key agencies involved in provision and payment of HIV prevention and care services. Federal respondents also discussed several personal reasons for their participation including their passion for HIV prevention and care and opportunities to expand professional networks within and outside of their home agency.



### Collaboration

Respondents from all three federal agencies reported gaining professional connections as a valuable resource for their work. Even though newly formed relationships across agencies were thought to be more informal, it was still perceived as beneficial.

“I’m not sure we made the structural part work quite as well yet, but the personal is a start. . . . Just for example, yesterday we have a project we’re starting . . . and we want to bring the Medicaid and Public Health folks together. . . . I was able to email the colleagues that I worked with in the Affinity Group, say this is what we’re looking for, and it turns out one of them was super interested. Wonderful. We have a CMS representative.”

- Federal Agency respondent

Several other federal respondents expressed intention to leverage new connections for projects outside of HIV, such as hepatitis C, immunization, etc.

The HIV Affinity Group also brought together people within the same agency who didn’t normally work together.

“Where we normally haven’t worked together in anything, this particular project brought us together.”

- Federal Agency respondent

It was also noteworthy that federal respondents with no previous experience in cross-agency collaborations reported gaining knowledge, confidence, and a desire to pursue more opportunities involving multiple federal agencies in the future.

“I think I will probably seek more opportunities to work outside of my agency or work with other agencies. I think this showed that we could do something for such a long period of time and actually be successful at it. I think that’s probably the thing I gained the most.”

- Federal Agency respondent



## Knowledge

Federal respondents’ reported gaining knowledge about each other’s programs and policies and finding value in better understanding agency acronyms, organizational culture, and funding mechanisms. Understanding cross-agency differences was suggested as an important precursor for establishing effective cross-agency collaborations and thus, should occur as early as possible.

Federal respondents noted the differing fiduciary and policy relationships between federal and state agencies and how it affected state participation in the HIV Affinity Group. CDC and HRSA fund state public health departments through cooperative agreements and other mechanisms while Medicaid operates more as an insurance company that “pays for services”.

“So it’s a different mindset for sure that trickles down to the employees that work for the agency.”

- Federal Agency respondent

Another difference mentioned was organization around disease areas. While public health staff are often compartmentalized by disease area, Medicaid staff are responsible for a range of health conditions and health services. Although Medicaid is the largest payor of HIV care, HIV is a small portion of Medicaid’s overall portfolio. As a result, federal participants observed that CMS had less leverage to influence individual state Medicaid agency actions.

Federal respondents gained a better understanding of the context in which state level programs and policies operate and the local contextual factors that influence these programs and policies. One respondent observed that frequent staff turnover and budget constraints affected states’ ability to move funded projects forward.

“For me in particular, who hasn't worked in the state and local government, it was really interesting to see how much work they need to support these ideas because their funds are so limited and their human capital is also limited. Because they have a lot of people who cycle in and out, they lose institutional knowledge pretty regularly. When you put forth these sort of grand ideas, knowing that even these little things, like understanding who's in charge of IT within your organization, takes sort of a lot more time than you would expect it to take.”

- Federal Agency respondent

However, as a result of the HIV Affinity Group, federal respondents felt better positioned to provide the support needed by state programs.

“I think it's been very educational for us, too. It's not that simple. It's not that straightforward. There's a lot of different policy and resource components in there, and I think, I hope, that it's given us a better idea of what really needs to happen on our end to support states.”

- Federal Agency respondent

### Impact of one federal voice on states

Federal respondents noted that bringing multiple federal agencies together to co-manage the HIV Affinity Group and operate as “one federal voice” encouraged state agencies to break down silos and work together. This sentiment was affirmed by state feedback received at the close-out meeting.

“We mirrored what we were asking the state teams to do, which is work across their agencies, respective agencies or even governments.”

- Federal Agency respondent

### Leveraging federal resources

Federal respondents cited the opportunity to leverage multiple sources of knowledge and resources as a benefit of participating in the HIV Affinity Group.

The HIV Affinity Group capitalized on the strengths of each agency. For example, CDC respondents spoke about the opportunity to show the relevance of HIV surveillance data for program improvement. For CMS respondents, the evaluation was important for demonstrating the value of affinity groups. More generally, federal respondents noted that lessons learned from the HIV Affinity Group had the potential to be translated into improved internal programs.

“It’s a great asset for any public health organization right now . . . organizations can chip in with either financial resources or human resources [to] achieve goals . . . .”  
- Federal Agency respondent



### Lessons learned

#### Shared vision

Federal respondents reported the importance of having a clear vision of what to accomplish in the one-year period. Having concrete shared goals and a focused direction helped the project to move faster.

“This was very much a “we know what we want to do, we know how we can get this done, so let’s move through and get it moving”, so I think there was a high level of commitment from all the federal agencies and the people involved to really get this started and not have it be sort of a long drawn out launch.”  
- Federal Agency respondent

#### Planning and flexibility

Federal respondents indicated that comprehensive planning was essential for managing the HIV Affinity Group. However, they also mentioned several areas that may have needed more planning including federal capacity to support participating states and how best to end the project and sustain any gains.

Federal respondents also expressed the need to remain flexible throughout the project and adjust strategies based on emergent needs and challenges. For example, states were grouped into learning communities based on initial assessment of their project plans. However, as project plans were implemented, it became clear that some states could benefit from the information shared in the other learning communities. In response, state participants were invited to attend other learning community calls if interested. One suggestion for the future was to have open learning communities.

Federal partners also expressed new appreciation for the challenges associated with providing the right mix of individualized technical assistance and peer-to-peer learning opportunities to states. Some federal respondents felt that the technical assistance process as a whole was not efficient and could have been more tailored to state needs. In one federal respondent's opinion, the "best" strategy for providing support to states depended on the need: given similarities across states around HIV surveillance and reportable data pieces, benefits from learning via state-to-state exchange outweighed individualized technical assistance. By contrast, questions about state Medicaid policy were better addressed through individualized technical assistance since solutions need to be developed within specific state policy context.

### Timely communication

Federal respondents also commented on the importance of frequent and open communication for effective federal collaboration. Meeting regularly about project issues (e.g., barriers to be resolved) was also important to keep all key partners informed. For example, open communication regarding a lapse in NASHIP resources mid-project had little effect on the states because the federal partners worked collaboratively to keep activities (e.g., monthly calls, webinars) moving without interruption.

“I think one of the strengths and one of the benefits of the HIV Affinity Group is that the three federal agencies and those of us who were very involved in the initial startup, as well as getting it sustained, were transparent about those challenges with each other and were respectful of our need to work that through internally and communicate with each other about where things were, so I think there was an incredible level of communication that helped us move through a lot of those challenges.”

- Federal Agency respondent

### Shared resources

Federal respondents thought that resources and responsibilities were shared equally across all three agencies leading to successful implementation of the project.

“Each of us assumed different responsibilities to carry out, to make the project successful, so that it wasn't all on one person's shoulders. And so, that was very helpful in terms of strengthening the partnership, developing it, and also reinforcing it.”

- Federal Agency respondent

NASHP was mentioned as an additional and important resource for federal partners; its assistance with project management was especially important given of the large number of states participating in the HIV Affinity Group. However, NASHP's role also introduced some complications. Since NASHP was funded under a cooperative agreement with one of the agencies, only one of the three agencies could formally delegate tasks to NASHP.

And because federal staff had underestimated the level of state interest in the group, the process for states to request technical assistance from NASHP became more formal and the hours available to each state for technical assistance more limited.

### Leadership support

Almost all federal respondents noted the importance of federal leadership buy-in and support throughout the project period. Such support was needed to ensure sufficient allocation of resources to support HIV Affinity Group. The benefit of leadership involvement throughout the project was seen as tool to boost staff commitment and motivation because “if those people [leaders] prioritize the work then the people lower in the chain will also prioritize it.”

“Definitely what you need is leadership, high-level leadership support to allow for this. Because it's very time-consuming, and so, the partners who are involved in it need to have their supervisors or their leadership, their respective leadership's understanding and support to go ahead and make this a priority and carry these activities out. So that's critical.”

- Federal Agency respondent

## Discussion

Participation in the HIV Affinity Group created opportunities to establish and strengthen partnerships between Medicaid and public health at the state and federal levels. The HIV Affinity Group provided a structure and environment in which participants could:

- Meet regularly and identify the unique assets available to each agency brought to the table;
- Identify, learn from, and in some cases adapt promising practices from other states; and
- Pursue high impact structural and policy changes.

Prioritization of this effort by federal partners gave it credibility and helped states justify spending the time and resources needed to develop and implement their state action plans.

The HIV Affinity Group organization structure worked well, but federal and state respondents did identify potential improvements that could inform similar future initiatives. For example, respondents agreed that learning communities were needed to organize the large number of participating states but suggested that there should be more flexibility in implementation of the concept. Other HIV Affinity Group processes with potential for improvement include providing technical assistance, assigning roles and responsibilities, communicating information, and scheduling activities.

For most participating states, the types of projects included in the state action plans and the one year time period was unlikely to result in measurable improvements in rates of viral suppression and in health outcomes among persons living with HIV enrolled in Medicaid during the project period. For example, most of the states focused on infrastructure creation, policy formulation/adoption, and development of new structural relationships. These types of changes improve operational efficiency and effectiveness and, ultimately, population health outcomes. Moreover, no additional funding was provided to states for their participation in the HIV Affinity Group. Staff turnover, limited resources, competing priorities, and state Medicaid reforms were challenges to implementing the state action plan objectives.

Nonetheless, several shorter-term outcomes were observed. Of the 19 participating states, 13 established or built upon existing data use agreements to bring together and match Medicaid claims, surveillance data, and Ryan White data sets. The other 6 states continue to work on their agreements post HIV Affinity Group. About half of the states with data matching capabilities generated an HIV care continuum for specific groups or populations. NASHP has packaged this work ([Toolkit: State Strategies to Improve](#)

[Health Outcomes for People Living with HIV](#)) so that other states can take advantage of the outcomes of this process including lessons learned and best practices.

Ultimately, HIV Affinity Group provided an opportunity for both federal and state participants to build new relationships and to implement activities that will improve the health and well-being of persons living with HIV enrolled in Medicaid.



## References

1. Centers for Disease Control and Prevention. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2015. *HIV Surveillance Supplemental Report 2017*;22 (No. 2). <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published July 2017. Accessed July 13, 2018.
2. The INSIGHT START Study Group. Initiation of Antiretroviral Therapy in Early Asymptomatic HIV Infection. 2015. *New Engl J Med*. Vol 373 (9): 795-807.
3. Cohen MS et al. Prevention of HIV-1 infection with early antiretroviral therapy. 2011. *New Engl J Med*. Vol 365 (6): 493-505.
4. Henry J. Kaiser Family Foundation. Medicaid and HIV (Fact Sheet). October 2016. <http://files.kff.org/attachment/Fact-Sheet-Medicaid-and-HIV>. Accessed July 13, 2018.
5. National HIV/AIDS Strategy for the United States: Updated to 2020. Federal Action Plan. December 2015. <https://www.hiv.gov/sites/default/files/nhas-2020-action-plan.pdf>. Accessed July 13, 2018.
6. Issue Brief. Unique Agency Features and the Components of Medicaid-Public Health Partnership. <http://www.astho.org/Health-Systems-Transformation/Medicaid-and-Public-Health-Partnerships/Learning-Series/Unique-Agency-Features-Issue-Brief/>. Accessed November 28, 2018.
7. Frey BB, Lohmeier JH, Lee SW, and Tollefson N. 2006. Measuring Collaboration among Grant Partners. *Am J Eval*. Vol 27 (3): 383-392.
8. HIV Care Continuum. <https://www.hiv.gov/federal-response/policies-issues/hiv-aids-care-continuum>. Accessed August 10, 2018.

## Acknowledgements

This report was prepared by Michelle Nichole Charlene Browne (CMS); Janet Heitgerd & Ekaterine Shapatava (CDC); and Pamela Klein & Ijeamaka Okoye (HRSA).

We would like to acknowledge Don Compton (evaluation consultant), Aisha Rios (evaluation consultant) and Jenny Lyons (data visualization consultant) for their assistance with the evaluation and report.

Finally, we would like to thank the HIV Health Improvement Affinity Group participants from the 19 states, NASHP, CDC, CMS, HRSA, and OHADIP for their time, hard work, and collaborative efforts to develop and implement action plans to increase viral suppression and improve health outcomes for persons living with HIV enrolled in Medicaid.

# Appendices

## Appendix 1: Program Description

Over the one-year project period, each of the 19 states participating in the HIV Affinity Group developed and implemented a state strategy to increase viral suppression for PLWH. Participating states developed action plans that reflected their state-specific goals and objectives. The plans were developed as a joint effort between state public health department and state Medicaid personnel. Federal partners supported implementation of those action plans through a number of activities, including review and feedback on state action plans, state specific technical assistance, and both didactic and peer-to-peer learning activities.

Overwhelming state interest necessitated some sort of grouping of states (typical prior affinity group size was about 8 to 10 states). Initial review of the plans revealed three main interest areas: data linkage and outcomes, data analysis and unitization, and provider engagement. The states were grouped by these interest areas into “learning communities” to facilitate topic-specific discussions and group activities.

- *Data Linkage and Outcome Learning Community* focused on instituting or expanding currently limited data-sharing activities, as well as analyzing these data to identify targets for performance improvement.
  - This learning community included California, Georgia, Iowa, Maryland, North Carolina and Wisconsin.
- *Data Analysis and Utilization for Delivery System Improvement Learning Community* focused on using data to identify quality-improvement opportunities.
  - This learning community included Illinois, Louisiana, Massachusetts, New York, Rhode Island, and Washington.
- *Provider Engagement and Quality Improvement Learning Community* focused on improving clinical outcomes and achieve greater viral load suppression rates through increased efforts to engage providers and improve quality of care.
  - This learning community included Alaska, Connecticut, Michigan, Mississippi, Nevada, New Hampshire, and Virginia.

## Activities

During the one-year project period, the following activities were conducted to assist state participants with implementing their action plans.

### In-person meetings

Two in-person meetings were held. The HIV Affinity Group kick-off meeting was in held in Washington, DC, in December 2016, and the close-out meeting was held in Portland, OR, in October 2017.

### Webinars (not learning community specific)

HIV Affinity Group participants were invited to attend 10 webinars. The webinar topics were developed with input from participants.

Month Year	Topic
October 2016	HIV Health Improvement Affinity Group Kickoff Webinar
November 2016	Developing Action Statements
January 2017	Data, Delivery, and Decisions as Levers for Enhancing Whole-Person Care for People Living with HIV: Lessons from the Ruth M. Rothstein CORE Center
February 2017	The Medicaid Program: An In-Depth Look
February 2017	State Health Department HIV Programs: An In-Depth Look
March 2017	Data Transfer and Use: Navigating Federal and State Laws and Regulations
May 2017	Data Sharing and Use: Creating Platforms for Exchange, Insight, and Action
July 2017	How Data Visualization Efforts Impact Care and Decision Making
August 2017	Improving Quality of Care for Medicaid Beneficiaries Living with HIV: Strategies to Engage Managed Care Plans and Providers
December 2017	Increasing Rates of Virologic Suppression: Promising Practices from HIV Health Improvement Affinity Group States

### Learning community teleconferences (including peer-to-peer formal presentations)

Starting in March 2017, CDC, CMS and HRSA organized bimonthly learning community calls. States led these calls using questions developed by federal partners to promote peer-to-peer sharing. States used the calls to provide updates on program goals and accomplishments, as well as to actively problem solve challenges. Both during and at the close of each call, participants were encouraged to reach out to peers and to federal partners for guidance, support, and technical assistance.

### Monthly digests

NASHP developed monthly learning community newsletters to sustain participants' engagement in the HIV Affinity Group. The monthly digests, summarize previous month activities, provided notice of upcoming activities, and other information.

### HIV Affinity Group website

NASHP developed a password protected website that was only accessible to HIV Affinity Group participants and federal partners. The website included call notes, slide sets, and webinar recordings.

### Individual technical assistance

The federal team coordinated responses to technical assistance requests NASHIP received from participating states. During the project period, federal partners responded to one or more technical assistance requests around topics such as developing and implementing data sharing agreements, and providing specific examples of coding procedure, diagnosis, and drug codes to identify persons with HIV and HIV-related medical care within Medicaid.

### Blog posts (HIV.gov)

OHAIDP administers HIV.gov, a cross-government web site that featured four informational blog posts about the HIV Affinity Group, including posts about the launch of the affinity group, its organization and purpose, and the development of a toolkit to help state Medicaid programs and health departments to work together to improve viral suppression rates among people living with HIV.

Date	Post
June 24, 2016	<a href="#"><u>CMS, CDC, &amp; HRSA Launch HIV Health Improvement Affinity Group for State Medicaid Programs</u></a>
December 5, 2016	<a href="#"><u>CMS, CDC &amp; HRSA Host State Medicaid &amp; Public Health HIV Health Improvement Affinity Group</u></a>
December 30, 2016	<a href="#"><u>HIV Health Improvement Affinity Group</u></a>
January 24, 2018	<a href="#"><u>Toolkit Features State Strategies to Improve the Health of People with HIV</u></a>

## Appendix 2: Evaluation Methods

The HIV Affinity Group was evaluated by a core team of staff from CDC, CMS, and HRSA, with assistance from independent contractors and input from participating states. This was the first formal evaluation completed for a Medicaid Affinity Group activity.

The proposed evaluation approach was presented at the December 2016 in-person meeting, followed by conference calls with volunteers from participating states to help refine the evaluation plan. The evaluation plan was finalized in March 2017. OMB approval for data collection was obtained in August 2017 (OMB 0920-0879, expiration date 1/31/2021).

The purpose of the evaluation was to assess the processes and short-term outcomes associated with the HIV Affinity Group, including whether the affinity group model facilitated new or enhanced processes or structures that helped participants achieve the goal of the HIV Affinity Group, including objectives outlined in their state action plans.

There were four questions underlying the evaluation:

1. To what extent, and how, did the HIV Affinity Group create opportunities to establish or strengthen partnerships between state Medicaid agencies and state public health departments?
2. How useful were the HIV Affinity Group activities to states in implementing their action plan?
3. What were the lessons learned by states in implementing their action plan?
4. To what extent, and how, did the HIV Affinity Group contribute to improved collaboration among federal partners?

The evaluation was conducted in two phases. The first phase (Fall 2017) focused on the experiences of state public health department and state Medicaid agency staff from the 19 participating states. The second phase (Spring 2018) focused on the experiences of the federal partners from CDC, CMS, and HRSA.

### Phase 1: State Public Health Department and State Medicaid Agency Participants

A web-based survey and telephone interviews were used for data collection. NASHP's list of HIV Affinity Group contacts was used as the sampling frame (current as of August 2017). A total of 109 state public health department and state Medicaid individuals from 19 states were on the list, of which 63 (58%) were identified as affiliated with a state public health department and 46 (42%) with a state Medicaid agency. The number of contacts per state ranged from 2 to 11. Position titles included epidemiologist, analyst, program administrator, program deputy director, program director/chief, program manager, and program specialist.

A link to the web-based survey was emailed to the 109 HIV affinity group participants on the contact list. The survey used both quantitative and qualitative elements to assess following areas:

- Opportunity to establish or strengthen state partnerships
- Usefulness of the HIV Affinity Group activities
- Lessons learned from participating in the HIV Affinity Group

Of the 109 emails sent, 29 participants responded.<sup>2</sup> Twelve participants could not be contacted (e.g., email undeliverable or out of office for survey window timeframe) or reported not being involved enough to provide feedback. The overall response rate was 30% (29/97). By agency affiliation, the response rate for state public health departments was 36% and state Medicaid agencies 20%. One respondent did not identify an affiliation. The data linkage and outcome learning community had the highest response rate (42%), followed by data analysis and utilization (29%), and provider engagement and quality improvement (21%).

Telephone interviews were used to solicit additional information on the HIV Affinity Group experiences of state public health department and state Medicaid agency participants. A total of 12 individuals across both state public health department and state Medicaid agency HIV Affinity Group participants were purposively sampled to be interviewed. Four were selected from each of the three learning communities. The interviews focused on the following topics:

- Value of participating in the HIV Affinity Group
- Opportunity to establish or strengthen state partnerships
- Lessons learned
- Suggestions for improving the HIV Affinity Group

An email invitation to participate in a 30-minute telephone interview was sent to 12 HIV Affinity Group participants from 9 states. Telephone interviews were conducted with 10 HIV Affinity Group participants from 8 states. Two participants could not be scheduled in the interview window timeframe. Of the 10 interviewees, 5 were affiliated with a state Medicaid agency and 5 were affiliated with a state public health department. By learning community, there were 4 interviewees from the Data Linkage and Outcome Learning Community, 2 from the Data Analysis and Utilization Learning Community, and 4 from the Provider Engagement and Quality Improvement Learning Community.

---

<sup>2</sup> Feedback from the states at the second in-person meeting suggested that about half of the 109 persons on the master state teams list were actively engaged across the entire project period and the others were included for information only purposes or for a specific aspect of the action plan. This likely contributed to the low web assessment response rate.

## Phase 2: Federal Agency Staff

Ten federal respondents, with at least two persons from each agency plus members of the evaluation team, were purposively selected to be interviewed. The interviews focused on the following topics:

- Benefits of federal collaboration for you, your agency, and for states participating in the HIV affinity group?
- Challenges and lessons learned?

An email invitation to participate in a 30-minute telephone interview was sent to 10 federal agency staff from CDC, CMS, and HRSA. All agreed to participate. Of the 10 interviewees, 4 were affiliated with CDC, 3 with CMS, and 3 with HRSA.

## Data Analysis

Quantitative data were analyzed using Microsoft Excel. Telephone interviews were transcribed and coded for major themes. Meeting notes and materials submitted by states reflecting end of the year achievements were also reviewed. The results are presented by the overarching themes that emerged from the quantitative and qualitative analyses of the web survey and telephone interview data.