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# Short-Term Outcomes and Lessons Learned From the Federal HIV Health Improvement Affinity Group for State Medicaid/Children's Health Insurance Program Agencies and State Health Departments

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## Abstract

**Background:** Medicaid is the single largest source of health care coverage for people living with HIV (PLWH) in the United States. Therefore, high-quality HIV care and associated viral suppression among Medicaid beneficiaries have the potential to greatly impact the HIV epidemic. The HIV Health Improvement Affinity Group (HHIAG) supported state efforts to improve health outcomes for PLWH enrolled in Medicaid through new or enhanced collaborations between state public health departments and state Medicaid agencies.

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**Methods:** Supported by multiple federal health agencies for 1 year, state health department and Medicaid staff from 19 states participated in state-to-state learning and sharing of promising approaches. This evaluation assessed the HHIAG's processes, short-term outcomes, and lessons learned through review of state materials, a web survey, and telephone interviews.

**Results:** Of the 19 states, 13 (68%) ultimately established new, or refined existing, data-sharing agreements between Medicaid and public health departments. Nearly all states with data-sharing agreements successfully matched the data or streamlined the data-matching process (n = 12/13). Two-thirds of states (67%, n = 8/12) with matched data generated an HIV care continuum for state Medicaid/Children's Health Insurance Program beneficiaries; 75% (n = 6/8) of these states also initiated quality improvement activities.

**Conclusions:** The HHIAG created an unique opportunity for multiple federal agencies and states to collaborate and implement data-driven, state-specific solutions to improve care delivery and, ultimately, clinical outcomes for PLWH. The HHIAG model has the potential to be replicated to address other public health issues that cross agency and institutional boundaries, such as hepatitis C.

### Keywords

HIV; Medicaid; affinity group; care continuum; data to care; collaboration

## INTRODUCTION

Of the estimated 1.1 million Americans living with HIV in 2016, 85% were aware of their HIV infection; of those aware of their HIV infection, 60% were virally suppressed.[1,2] 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.[3–5] Medicaid is the single largest source of care for PLWH.[6] Therefore, high-quality HIV care and viral suppression among Medicaid beneficiaries living with HIV have the potential to greatly impact the HIV epidemic in the United States.

The Federal National HIV/AIDS Strategy: Updated to 2020, called on the Centers for Medicare and Medicaid Services (CMS), the Centers for Disease Control and Prevention (CDC), and the Health Resources and Services Administration (HRSA) to collaboratively launch an affinity group focused on improving HIV health outcomes for PLWH—the HIV Health Improvement Affinity Group (HHIAG).[7] The HHIAG built upon an affinity group model, which was developed by CMS to address topics of common interest to states through state-to-state learning and enhanced technical assistance to improve delivery of preventive health care to people enrolled in Medicaid and the Children's Health Insurance Program (CHIP).[8] The goal of the HHIAG was to support state efforts to increase viral suppression and to improve health outcomes for PLWH enrolled in Medicaid/CHIP through collaborations between state public health departments and Medicaid/CHIP agencies.

Staff from the supporting federal agencies (CMS, CDC, and HRSA) anticipated that participants would benefit from state-to-state learning and sharing of best and promising approaches. In addition, states would develop stronger collaborative relationships among

Medicaid/CHIP programs, state public health departments, and other partners (public or private; federal, state, or local) who are well positioned to advise and support HIV-related efforts for maximum impact.

States developed their own approaches and individualized action plans to improve viral suppression among Medicaid/CHIP beneficiaries. Most states built upon the concept of "Data to Care," a public health strategy using HIV surveillance data and other data sources to identify HIV-diagnosed individuals not in care, link them to care, and support progress along the HIV care continuum.[9] These states applied "Data to Care" strategies to strengthen data sharing and utilization between the Medicaid/CHIP and state public health departments, measure critical outcomes of HIV care, and strategically plan health improvement activities for PLWH. This article presents outcomes, including successes, challenges, and lessons learned throughout the HHIAG initiative from October 2016 to December 2017.

## METHODS

### Initiative Description

The HHIAG was a U.S. Department of Health and Human Services initiative jointly supported by CMS, CDC, and HRSA, in collaboration with the Office of HIV/AIDS and Infectious Disease Policy, and in partnership with the National Academy for State Health Policy (NASHP). All states that completed expression of interest forms, which outlined proposed project and goal(s), identified team members, and indicated support of both the state AIDS Director and Medicaid leadership, were accepted into the HHIAG. No additional funding was provided to states for their participation.

State health department and Medicaid/CHIP staff from 19 states (Fig. 1)—Alaska, California, Connecticut, Georgia, Illinois, Iowa, Louisiana, Maryland, Massachusetts, Michigan, Mississippi, Nevada, New Hampshire, New York, North Carolina, Rhode Island, Virginia, Washington, and Wisconsin—worked together on the activities of the HHIAG. These 19 states accounted for 50% of new diagnoses in 2016 and almost 54% of PLWH at the end of 2015 in the United States.[10]

States developed individual action plans that outlined their project goals and objectives, as well as strategies and action items needed to accomplish their goals. The plans provided a framework of anticipated state activities and helped federal partners identify areas for technical assistance and program support. Each state was assigned into 1 of 3 learning communities based on common themes outlined in the action plans. Members of the Data Linkage and Outcome Learning Community (6 states) instituted or expanded data-sharing activities and analyzed these data to identify targets for performance improvement. States in the Data Analysis and Utilization for Delivery System Improvement Learning Community (6 states) used linked data assets to identify areas for system improvements. Finally, the Provider Engagement and Quality Improvement Learning Community (7 states) engaged providers and improved the quality of care to achieve higher viral suppression. Recognizing the potential overlap of the learning community interest areas and evolution of state activities over time, participants had access to affinity group webinars, calls, and materials for all learning communities.

States participated in a variety of activities to help them achieve the goals outlined in their action plans, including didactic, peer-driven, and state-specific technical assistance. Federal staff coordinated 9 webinars based on the technical assistance needs identified from the action plans and during learning community calls, including process improvements, data-sharing and data visualization, and quality improvement (Table 1). Two in-person meetings and recurrent learning community calls provided forums to share best practices, lessons learned, challenges faced, and strategies to implement policy and program changes. States could request individualized technical assistance around state-specific issues. HHIAG participants also had opportunities to share best practices and lessons learned, and communicate with other participating states and states outside of the HHIAG, including monthly newsletters specific to each learning community, blog posts on the NASHP website, and issue briefs.

Resources developed for, and lessons and best practices that emerged from, the HHIAG were ultimately packaged into a toolkit, entitled “State Strategies to Improve Health Outcomes for People Living with HIV,” which was released nationally in December 2017.[11] This toolkit provides state officials with resources and reference materials to guide efforts to share and use data, collaborate with stakeholders and make policy and program changes to improve the overall health of people living with HIV. It includes nearly the webinars and publications developed for the HHIAG states and is continually updated as more HIV-related resources are developed.

## Initiative Evaluation

This evaluation assessed the processes, short-term outcomes, and lessons learned associated with the HHIAG. Specific outcomes of interest included whether states successfully established data-sharing agreements, matched data across public health and Medicaid/CHIP, and developed HIV-care continua using matched data, including whether or not states successfully estimated the proportion of Medicaid/CHIP beneficiaries who achieved viral suppression. Additional outcomes included the formation and evolution of collaborations, acquisition of knowledge over the project period, and anticipated sustainability of accomplishments.

The mixed-methods evaluation was conducted through review of meeting notes and materials submitted by states reflecting end of initiative achievements, OMB (#0920–0879). Quantitative information was collected through the web survey, while both the web survey and telephone interviews collected qualitative information. The web survey and telephone interviews solicited state experiences and perspectives about the development of cross-agency partnerships and collaboration, the utility of HHIAG activities and federal support in implementing state action plans, and lessons learned while implementing state action plans.

Individuals on the HHIAG contact list, including both core team members and less-involved staff, were emailed to participate in the survey. The overall response rate was 30% (n = 29/97); 36% of state health department staff and 20% of state Medicaid/CHIP agency staff responded. Approximately three-quarters (72%, n = 21) of respondents were affiliated with state health departments, 24% (n = 7) were affiliated with Medicaid/CHIP agencies, and 4% (n = 1) did not indicate an affiliation. Twelve individuals who completed the web survey

were purposively selected for a 30-minute telephone interview, representing state health department and state Medicaid/CHIP perspectives and all 3 learning communities; 10 individuals, representing 8 different states, agreed to participate (83% response rate).

Quantitative data were processed and analyzed using Microsoft Excel. Telephone interviews were recorded and transcribed. Qualitative data were coded for major themes using NVivo 10. The initial codebook was created based on the evaluation questions and review of several interviews; additional codes were added as they emerged from the data. All qualitative data were coded by one staff member; cross-cutting themes were discussed among evaluation staff to reach final consensus.

## RESULTS

### Data-Related Outcomes

Most state action plans prioritized better exchange and use of cross-agency data. Thirteen (68%) of the 19 states participating in the HHIAG ultimately established new, or refined existing, data-sharing agreements between Medicaid and public health departments. Establishing new data use agreements took significant time, because of identifying how the data would be used to achieve program goals, as well as administrative hurdles and time to coordinate meetings with the appropriate staff.

For states that established or refined a data-sharing agreement, 92% (n = 12/13) successfully matched their data or streamlined their data-matching processes to identify PLWH who were potentially not accessing HIV medical care. In most cases, states matched Medicaid/CHIP data with HIV surveillance data and, in some cases, HRSA's Ryan White HIV/AIDS Program (RWHAP) data. Generally, state public health departments gained access to Medicaid data, but some bidirectional data sharing occurred. Although one state was not able to exchange data in the 1-year project period, their cross-agency collaborations resulted in a policy change that newly funded managed care organizations (MCOs) in that state are now mandated to share data to support quality improvement initiatives.

Over half of the states (67%, n = 8/12) with matched data generated an HIV care continuum for state Medicaid/CHIP beneficiaries, overall, based on population characteristics, or by enrollment status in MCO or non-MCO plans. States used these care continua to identify targets for performance improvement. Most (75%, n = 6/8) of these states also initiated quality improvement activities during the HHIAG including the following:

- Informing Medicaid providers about the importance of measuring the HIV care continuum, barriers for PLWH linking to care and staying engaged in care, and other support programs available for PLWH;
- Forming a "mini" HIV-affinity group for statewide Medicaid MCOs to identify and share best practices such as targeted outreach, care coordination, and clinical services; and
- Developing customized fact sheets for MCOs including data on disparities in viral suppression by race, sex, and geography.

## Cross-Agency Partnerships and Collaboration: Mitigating Differences and Leveraging Expertise

Both state Medicaid/CHIP and state public health department respondents who were surveyed viewed the HHIAG as an opportunity to strengthen collaboration, particularly around the use of different agency data sources. Overall, approximately half of respondents reported forming new collaborations (50% of state Medicaid/CHIP respondents, 44% of state public health department respondents).

Respondents were asked to rate the strength of their cross-agency collaborations on a scale of 1 (no interaction) to 5 (coalition).[12] Respondents retrospectively self-reported an increase in the strength of cross-agency collaboration over the course of the HHIAG; state Medicaid/CHIP respondents reported an increase from 3.1 to 3.8 and state health department respondents reported an increase from 2.7 to 3.3 (Fig. 2). Respondents anticipated that the strength of their collaborative relationships would increase in the future.

> "Before 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."

More than half of respondents reported gaining new knowledge and access to information about organizational culture, priorities, and policies of their partner agency; HIV prevention and care programs; funding at the federal level; and provider engagement strategies and quality improvement initiatives.

> "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."

Differences in organizational missions and cultures were reflected in agency systems and data collection. Consequently, states needed to develop an understanding of the data collected by each agency to assess their usefulness in generating an HIV care continuum and ensure their correct interpretation (e.g., HIV medication carve outs, International Classification of Diseases (ICD) 10 data codes, NDC drug codes).

> "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."

Respondents explained that the path to collaboration was not always straightforward and required significant investment from both agencies. Participants emphasized the need to acknowledge partner organizational differences (e.g., culture, policies, and priorities) and set appropriate expectations early in the process.

### Agency and Federal Support

The pace at which states implemented their action plan was often determined by available state resources (including staff time) and evolving state priorities. Participation in HHIAG activities added workload to an already-taxed workforce in both agencies without any clear offsetting benefits (eg, additional funding). Although direct participants saw the value in the work of the HHIAG, other agency staff did not always see the immediate benefit. Interviews with state participants noted that endorsement of HHIAG activities from federal partners and NASHP gave credibility to the HHIAG and helped to justify the time and resource investment.

> "[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."

As the work progressed, other agency staff came to value their states' participation. In one jurisdiction, successful matching of Medicaid/CHIP claims and HIV surveillance data allowed the state to assess how many PLWH were enrolled in Medicaid/CHIP and whether these individuals were receiving HIV care and virally suppressed. Agency staff viewed this information as critical to better target limited resources to PLWH who were not regularly seeking HIV care or have other barriers to care.

> "We want to be able to let them know if their patients are in care and have received viral suppression. We're doing it as an aggregate right now. So, hopefully it'll work more to an individual level. If we find someone out of care, and if they are a Medicaid client you know, how can the Medicaid case managers maybe help to get that person back into care."

### Sustainability of Accomplishments

Nearly all survey respondents reported that they were "somewhat likely" or "very likely" to sustain their accomplishments from the HHIAG (n = 6/6, 100% of Medicaid/CHIP respondents; n = 15/16, 94% of state public health department respondents; Table 2).

> "This type of work is going to continue, it's iterative and we are going to keep at it."

## DISCUSSION

The HHIAG created a unique opportunity for federal agencies and states to partner and implement data-driven, state-specific solutions to address the common public health concern of viral suppression among PLWH using a "Data to Care" framework. Participants reported increased collaboration, knowledge sharing, and developed innovative approaches to improve the health of PLWH served by Medicaid/CHIP. State public health and Medicaid

agencies shared and matched their HIV data and developed HIV care continua specifically for Medicaid/CHIP beneficiaries. These care continua estimated the percentage of PLWH served by Medicaid/CHIP who were engaged in care and achieved viral suppression, an important metric for program monitoring and in the National HIV/AIDS Strategy.

Many states used their HIV care continuum to identify opportunities for program improvement and improve care delivery for PLWH in their jurisdiction. Since Medicaid is the largest source of care for PLWH, these improvements could increase HIV care engagement and viral suppression for a large proportion of PLWH within each state, ultimately having a positive impact on quality of life, life expectancy, and reducing HIV transmission.[3–5] Through these program improvements, routinely collected data can extend beyond its traditional role in program monitoring to improve the quality of care. Improving the quality of care can be a common priority for different agencies, resulting in cross-agency support to engage in innovative approaches.

At the conclusion of the HHIAG initiative, NASHP created a toolkit to provide state officials with resources to improve viral suppression among Medicaid/CHIP beneficiaries.[11] This toolkit is available to both participating states and other jurisdictions; the federal partners have also connected nonparticipating jurisdictions with resources and points of contact in states that successfully implemented their action plans. The lessons learned and best practices for developing and implementing performance improvement projects that address gaps along the HIV care continuum for Medicaid/CHIP beneficiaries can serve as a template for other states and jurisdictions. Application of the HHIAG framework could improve state efforts to address gaps along the HIV care continuum and improve health outcomes of Medicaid enrollees living with HIV.

The HHIAG evolved from previous initiatives that were supported by single federal agencies to foster collaborations among nontraditional partners and leverage existing resources to improve health care delivery and positively impact clinical outcomes. CDC’s Program Collaboration and Service Integration initiative worked with state health departments to strengthen work and integrate services related to the overlapping epidemics of HIV, viral hepatitis, other sexually transmitted diseases, and tuberculosis.[13] HRSA’s HIV/AIDS Bureau’s RWHAP Part F Special Projects of National Significance supports the development of innovative models of HIV care and treatment to respond to the emerging needs of clients served by the RWHAP through technical assistance providers and grants to RWHAP recipients.[14] CMS has used the affinity group model with state Medicaid/CHIP agencies to improve access to and the delivery of quality care for school-based health services delivery, tobacco cessation, and antipsychotic drug use in children.[8] However, the HHIAG is the first time these frameworks have been extended to a cross-agency initiative at both the state and federal agency levels.

The HHIAG initiative yielded lessons in partnership development for both the federal and state agencies involved. Regular communication between the states and federal agencies allowed the federal agencies to tailor the components of the HHIAG to meet specific state needs. When state agencies expressed limited knowledge about the other agency’s work, the federal partners developed webinars on “Medicaid for state public health agencies” and

"state health for Medicaid agencies". The communication and collaboration between the states allowed for participants to learn more about their counterparts and the challenges that they may encounter, identify applicable lessons learned, and develop strategies to implement in their own jurisdictions.

Creating the infrastructure for cross-agency partnerships required an investment of time and resources. A common limiting factor in the implementation of state action plans was the lack of additional funding for this initiative, while managing existing workloads and competing priorities. State staff were subject to shifting priorities and local policies that impacted their level of involvement. Agencies increasingly recognized the value of the time and effort for the HHIAG as state action plans goals were achieved. Federal support of the HHIAG and the connection of the HHIAG to the achievement of National HIV/AIDS Strategy goals further validated the activities of the HHIAG. Being mindful of the resource and time investment necessary to establish these partnerships may mitigate challenges that states may face as they embark on cross-agency initiatives based on the HHIAG model. Engaging local, state, and/or federal partner organizations and stakeholders may also benefit and support future affinity group initiatives.

This cross-agency affinity group model can be replicated to address other public health concerns and diseases, either through self-directed collaborations within states or through formal affinity groups with federal support. For example, Health and Human Services offices and agencies are collaborating to support the Hepatitis C Medicaid Affinity Group to increase the number and percentage of Medicaid beneficiaries diagnosed with hepatitis C virus infection who are successfully treated and cured. The Hepatitis C Medicaid Affinity Group includes 9 states; 6 of these states participated in the HHIAG.

Despite the positive outcomes and potential for replication demonstrated by this evaluation, this evaluation was limited in scope and response rate. Although respondents were confident that their organizations would sustain the accomplishments of the HHIAG and anticipated continually increasing cross-agency collaborations, this evaluation focused only on short-term outcomes and did not investigate longer-term accomplishments or collaboration evolution. In addition, only 30% of HHIAG participants responded to the web survey invitation. Therefore, the results of this evaluation may not be representative of the experiences of all participants.

Public health issues do not impact a single-state or federal agency; rather, they impact multiple agencies and programs concurrently. Through data-driven collaboration based on the "Data to Care" framework, state public health agencies, state Medicaid/CHIP agencies, and federal partners took meaningful steps toward improving the health of Medicaid/CHIP beneficiaries living with HIV. Adoption HHIAG activities in other jurisdictions could lead to significant improvements in the national HIV care continuum. Future replication of the cross-agency affinity group model could positively impact health outcomes for a wide array of conditions and significantly improve population health.

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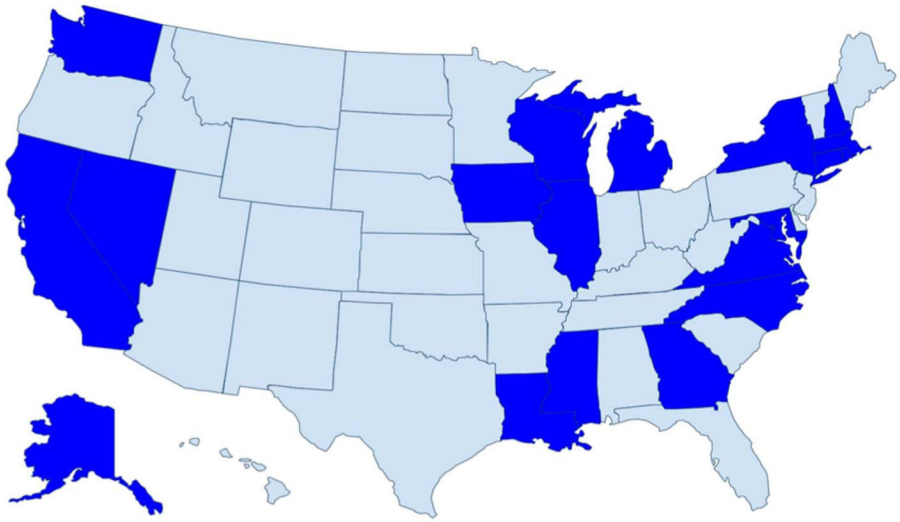
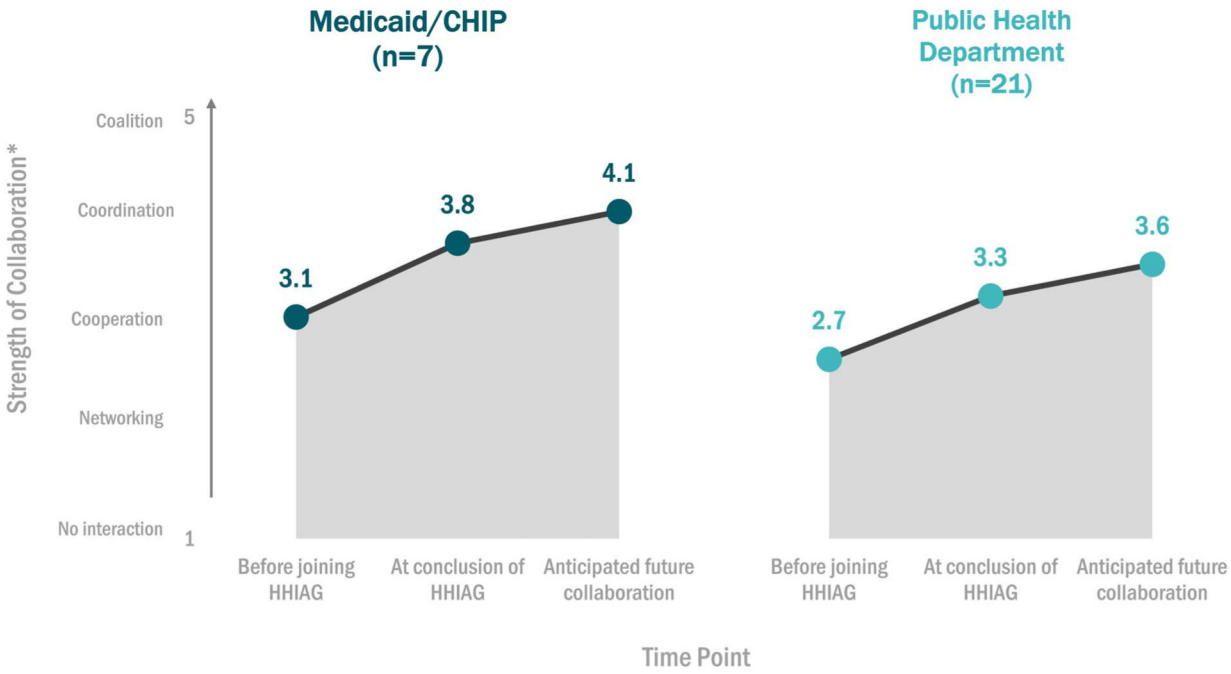


States in dark blue on the map are the states that formed the HIV Health Improvement Affinity Group--State health department and Medicaid/CHIP staff from the following 19 states: Alaska, California, Connecticut, Georgia, Illinois, Iowa, Louisiana, Maryland, Massachusetts, Michigan, Mississippi, Nevada, New Hampshire, New York, North Carolina, Rhode Island, Virginia, Washington, and Wisconsin.

**FIGURE 1.**
HHIAG states.




**Strength of collaboration scale from* Frey BB, Lohmeier JH, Lee SW, Tollefson N. Measuring Collaboration Among Grant Partners. *American Journal of Evaluation.* 2006;27(3):383-392.

**FIGURE 2.**

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

**TABLE 1.**

HHIAG Webinars and Meetings, October 2016–December 2017

| Date | Topic | Attendance |
|---|---|---|
| October 2016 | Kick-off webinar | 142 |
| November 2016 | Webinar: “Process improvement methods and tools” | 76 |
| December 2016 | In person meeting | 103 |
| February 2017 | Webinar: “State health department HIV programs: An in-depth look” | 49 |
| February 2017 | Webinar: “The medicaid program: An in-depth look” | 45 |
| March 2017 | Webinar: “Data transfer and use: Navigating federal exchange and state laws and regulations” | 65 |
| May 2017 | Webinar: “Data sharing and use: Creating platforms for exchange, insight, and action” | 41 |
| July 2017 | Webinar: “How data visualization efforts impact care and decision making” | 55 |
| August 2017 | Webinar: “Improving quality of care for medicaid beneficiaries living with HIV: Strategies to engage managed care plans and providers” | 50 |
| September 2017 | Webinar: “HIV viral load suppression measure listening session” | 48 |
| October 2017 | In-person meeting at the NASHP conference | 38 |
| December 2017 | Webinar: “Increasing rates of virologic suppression, promising practices from HHIAG states” (national) | 222 |

**TABLE 2.**

Likelihood of Sustaining the HIV Affinity Group Accomplishments, by Respondent Affiliation (September 2017)

| | Respondent Affiliation | | | |
|---|---|---|---|---|
| | **Very Likely (%)** | **Somewhat Likely (%)** | **Somewhat Not Likely (%)** | **Not Likely (%)** |
| State Medicaid/CHIP (n = 6) | 17 | 83 | 0 | 0 |
| State Public Health Department (n = 16) | 69 | 25 | 6 | 0 |