

# Using HIV Surveillance Data to Link People to HIV Medical Care, 5 US States, 2012-2015

Public Health Reports  
2018, Vol. 133(4) 385-391  
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DOI: 10.1177/0033354918772057  
journals.sagepub.com/home/phr



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## Abstract

**Introduction:** From 2012 through 2015, the Centers for Disease Control and Prevention (CDC) provided funding to 5 health departments for demonstration projects using HIV surveillance data to link people with newly diagnosed HIV to care. We assessed how well these health departments established linkage to care, how the demonstration projects helped them with this work, and if they sustained these activities after CDC funding ended.

**Materials and Methods:** We obtained quantitative and qualitative data on linkage-to-care activities from health department communications and progress reports submitted to CDC. We calculated and combined linkage-to-care results for the 5 health departments, and we compared these results with the combined linkage-to-care results for 61 health departments that received CDC funding for routine HIV prevention activities (eg, HIV testing, linkage to and reengagement in HIV care, HIV partner services) and for the same 5 health departments when they used only routine HIV prevention activities for linkage to care.

**Results:** Of 1269 people with a new HIV diagnosis at the 5 health departments, 1124 (89%) were linked to care, a result that exceeded the 2010-2015 National HIV/AIDS Strategy goal (85%), the CDC Funding Opportunity Announcement performance standard (80%), and combined results for the 61 health departments (63%) and the same 5 health departments (66%) using routine HIV prevention activities. Benefits of the projects were improved collaboration and coordination and more accurate, up-to-date surveillance data. All health departments continued linkage-to-care activities after funding ended.

**Practice Implications:** Using HIV surveillance data to link people with HIV to care resulted in substantial clinical and public health benefits. Our observations underscore the importance of collaboration among medical providers, public health staff members, community-based organizations, and people with HIV to ensure the best possible clinical and public health outcomes.

## Keywords

engagement, linkage to care, public health practice, surveillance data, HIV

In public health practice in the United States, surveillance data are used to guide screening, treatment, and prevention activities for people with various notifiable conditions.<sup>1-3</sup> However, whereas surveillance data have been used to monitor trends in HIV diagnoses and prevalence and to support the planning and distribution of funds at the population level, these data have not typically been used for screening, treatment, and prevention activities for people with HIV. This difference may be because of the lack of effective treatments for HIV until the mid-1990s, as well as concerns about HIV-related stigma, discrimination, confidentiality, ethics, and professional autonomy.<sup>2-8</sup>

In recent years, 3 key developments created a compelling rationale for the use of HIV surveillance data to ensure that people with HIV receive prevention services and

antiretroviral treatment. First, laboratories are increasingly reporting CD4 cell counts and viral load levels directly to health department surveillance systems.<sup>2,4,7</sup> These 2 laboratory parameters are considered acceptable proxies for

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engagement in HIV care when used at the population level,<sup>9-13</sup> and they may be useful for identifying people with HIV who are in need of medical treatment.<sup>14,15</sup> Second, antiretroviral treatment has led to viral suppression, resulting in improved health and prolonged life for those with HIV and reduced risk of HIV transmission to others.<sup>16,17</sup> Third, the amount of knowledge about people with HIV who are not engaged in care or not virally suppressed has increased.<sup>18-20</sup> Indeed, the substantial size of the population of those not receiving care or antiretroviral therapy may mean that *not* using available HIV surveillance data in efforts to improve engagement in HIV care could be unethical.<sup>2,4,6-8</sup>

The increased interest in using HIV surveillance data to improve outcomes among those with HIV triggered several federal efforts in the past several years. In 2010, the White House released the National HIV/AIDS Strategy (NHAS), one goal of which was to increase the percentage of people with newly diagnosed HIV who are linked to HIV medical care from 65% to 85% by 2015.<sup>21</sup> In 2011, the Centers for Disease Control and Prevention (CDC) updated its security and confidentiality guidelines to facilitate the sharing and use of surveillance data for HIV public health action.<sup>22</sup> After updating guidelines, CDC issued a Funding Opportunity Announcement (FOA) for the Comprehensive HIV Prevention Programs for Health Departments, with funds available in 2012,<sup>23</sup> and another for the National HIV Surveillance System, with funds available in 2013,<sup>24</sup> both of which encouraged health departments to use HIV surveillance data for linkage-to-care activities. The 2012 Comprehensive HIV Prevention FOA incorporated a linkage-to-care performance standard of 80%. This FOA involved 61 health departments that were funded for routine HIV prevention activities (Category A core funding; eg, HIV testing, linkage to and reengagement in HIV care, HIV partner services); 30 of these health departments were also funded for time-limited, non-research HIV prevention demonstration projects (Category C competitive funding). Finally, in 2014, CDC published *Recommendations for HIV Prevention With Adults and Adolescents With HIV in the United States*<sup>6</sup> and online information with technical assistance tools,<sup>25</sup> which also encouraged the use of HIV surveillance data to promote linkage to and retention in HIV medical care.

The main purpose of the Category C nonresearch demonstration projects was to provide services to people with HIV in day-to-day public health practice. We were particularly interested in examining the 5 health departments that received funding for demonstration projects that used HIV surveillance data to promote linkage to care. Because we did not know how health departments might conduct and sustain such activities, we conducted an assessment to learn how well health departments established linkage to care, how the demonstration projects helped the health departments establish linkage to care, and whether the health departments sustained the CDC-funded activities after funding ended.

## Materials and Methods

CDC funded the 2012 Comprehensive HIV Prevention Programs FOA demonstration projects from March 2012 through December 2015.<sup>26</sup> Of the 30 health departments that received funding for these demonstration projects, only those in 5 states (Alaska, Hawaii, Maryland, Minnesota, and Washington State) used HIV surveillance data to initiate the linkage to care of people with newly diagnosed HIV. Surveillance staff members in these health departments analyzed their HIV surveillance data to identify people with newly diagnosed HIV who were presumed not to be in care on the basis of the absence of data on CD4 cell count and viral load. The timing of this identification varied by health department (ie, people were identified upon report to the health department or on a weekly or monthly basis). Prevention program staff members in health departments or community-based organizations then either contacted the medical provider of record or located the affected person and helped the person establish access to care.

For this study, we defined linkage to care as attending an appointment with an HIV medical provider within 90 days of an HIV diagnosis, a definition consistent with the 2010-2015 NHAS and with guidance that CDC provided to health departments. To calculate the linkage-to-care results for the 5 health departments, we used the number of people who attended such an appointment (within 90 days of HIV diagnosis) as the numerator and the total number of people with newly diagnosed HIV within their jurisdiction as the denominator. This denominator included people who were linked to care more than 90 days after diagnosis and people who refused linkage-to-care services, and it excluded people who were already in care, had moved out of the health department jurisdiction, were deceased, or were unable to be located. Of the 5 health departments that we studied, 4 used a CD4 cell count or viral load test result from HIV surveillance data as a proxy for appointment attendance, and 1 used these laboratory tests as a proxy only when information about medical appointment attendance was unavailable.

To conduct the analyses, we used 2 main data sources: (1) records of communications between CDC and the health departments (eg, emails, meeting records) and (2) semiannual and final progress reports containing quantitative and qualitative data (from both the demonstration projects and the routine activities) submitted to CDC by the health departments. We used the qualitative data filed by the health departments to assess how the demonstration projects benefited their HIV prevention programs and helped establish linkage to care. We also used these data to assess whether health departments sustained their demonstration project activities after funding ended.

To gauge how well the demonstration projects linked people to care, we calculated the linkage-to-care results for each of the 5 health departments, and we compared the combined result for those departments with the NHAS linkage-to-care goal and the performance standard for the 2012

**Table.** US health department linkage-to-care outcomes for people newly diagnosed with HIV, during CDC-funded Comprehensive HIV Prevention Programs for Health Departments, 2012-2015

Funding Opportunity Announcement Activity <sup>a</sup>	Health Departments, No.	Time Period	Newly Diagnosed With HIV, No.	Linked to Care, No. (%)
Demonstration project <sup>b</sup>	5 <sup>c</sup>	March 2012–December 2015	1269	1124 (89)
Routine HIV prevention <sup>d</sup>	5 <sup>e</sup>	January 2013–December 2015 <sup>f</sup>	960	638 (66)
Routine HIV prevention <sup>d</sup>	61	January 2013–December 2015 <sup>f</sup>	28446	17965 (63)

Abbreviation: CDC, Centers for Disease Control and Prevention.

<sup>a</sup>CDC issued a Funding Opportunity Announcement (FOA) for the Comprehensive HIV Prevention Programs for Health Departments (FOA PS12-1201, funds available in 2012).<sup>23</sup> This FOA involved 61 US health departments that received funding for routine HIV prevention activities, 30 of which received additional and separate funding for time-limited, nonresearch HIV prevention demonstration projects.

<sup>b</sup>Of the 30 health departments funded for demonstration projects, 5 health departments conducted projects using HIV surveillance data to establish linkage to care for people newly diagnosed with HIV.

<sup>c</sup>Combined linkage-to-care results of the 5 health departments that conducted the demonstration projects using HIV surveillance data.

<sup>d</sup>Routine HIV prevention activities included HIV testing, linkage to care, reengagement in care, and HIV partner services.

<sup>e</sup>Combined linkage-to-care results of the same 5 health departments when using only routine HIV prevention activities.

<sup>f</sup>Only time period for which data were available and comparable to demonstration project data.

Comprehensive HIV Prevention Programs FOA. In addition, we compared the combined linkage-to-care results for the 5 health departments with the combined linkage-to-care results for the 61 health departments that received PS12-1201 funding for routine HIV prevention activities (eg, HIV testing, linkage to and reengagement in HIV care, HIV partner services). This group of 61 health departments included the 30 health departments that received additional funding for demonstration projects, 5 of which were the health departments that we studied. We had previously determined that the results from the 61 health departments were reasonable standards by which to judge linkage-to-care rates,<sup>26</sup> even though the 61 health departments that were funded for routine prevention activities determined linkage-to-care rates by using approaches that differed from those used by the 5 health departments that we studied.

Finally, because they were reported separately, we also compared the combined linkage-to-care results of the 5 health departments when they used HIV surveillance data with the combined linkage-to-care results of the same 5 health departments when they used only routine HIV prevention activities. Our comparisons involved the March 2012 to December 2015 demonstration project results and January 2013 to December 2015 routine HIV prevention activity results, because the latter were the only comparable data available.

Although the main focus of the demonstration projects in these 5 health departments was to use HIV surveillance data to support linkage-to-care activities, the health departments were also allowed to use data from other sources. For example, some health departments searched clinic records or sexually transmitted disease surveillance databases for updated information on current residence and contact information or for evidence of linkage to care. The health departments were also allowed to submit additional information in their progress reports to CDC. Of the 5 health departments in our study, 2 submitted data on viral load suppression (which they defined as <200 copies/mL) and reported viral load data that

were related to linkage-to-care activities in their demonstration project. Also, 2 health departments reported the number of people who were already in care, had moved, were deceased, and were unable to be located.

## Results

For the 5 health departments, 1124 of 1269 people with a new HIV diagnosis (89%) were linked to care (Table). Of 298 people in the 2 health departments that reported data on viral load, 250 (84%) demonstrated viral suppression, based on viral load data provided at or soon after the end of the project (ie, December 2015 from one health department and March 2016 from the other health department). The 2 health departments reporting detailed information about people who were excluded from our study denominator identified 350 people who were initially presumed to be out of care and, thus, sought for possible linkage-to-care services. Of these, we excluded from our study 111 (32%) people who were already in care, 24 (7%) people who were not able to be located, 18 (5%) people who had moved, and 3 (1%) people who were deceased.

Of the 5 health departments, 4 used additional data sources for information, 5 used HIV surveillance data for partner notification, and 1 worked with community-based organizations to link people to care. The most commonly reported examples of how these health departments benefited from their demonstration projects were (1) improved collaboration and coordination among surveillance staff members, HIV prevention program staff members, and medical providers (all 5 health departments) and (2) availability of more accurate, up-to-date surveillance data (all 5 health departments). As one example of the latter, the quality of surveillance data was improved because HIV prevention program or medical staff members interviewed patients or reviewed their medical records and then, as part of the project, gave the surveillance staff members information that was not previously in the HIV surveillance database (eg, current

location, HIV risk factors). Finally, we confirmed that all 5 health departments sustained their activities after the end of demonstration project funding by using alternate funding sources (eg, Ryan White, AIDS Drug Assistance Program, other state funding).

## Discussion

The 5 health departments that we studied conducted HIV linkage-to-care demonstration projects using HIV surveillance data, and they achieved a combined HIV linkage-to-care percentage (89%) that exceeded the NHAS national goal (85%), the 2012 Comprehensive HIV Prevention Programs FOA performance standard (80%), and the combined results from health departments that approached HIV linkage to care with other methods (63%). Of these 5 health departments, the 2 that documented data on viral load during the period of the demonstration project reported viral suppression in 84% of people, surpassing the viral suppression in 77% to 81% of people that was observed in the most recently available US surveillance data (reported in 2013 to CDC by 33 jurisdictions with complete laboratory data).<sup>10</sup> Furthermore, as a result of these demonstration projects, the 5 health departments reported that collaboration and coordination among surveillance staff members, HIV prevention program staff members, and medical providers improved and that HIV surveillance data became more accurate and up-to-date. Finally, experience gained from these demonstration projects was used to help create CDC's website pages that promote Data to Care, a public health strategy that uses HIV surveillance to support the HIV Care Continuum, by identifying people with HIV who are in need of HIV medical care or other services and linking them to these services.<sup>25</sup>

Our results indicate that these demonstration projects involving the use of HIV surveillance data were beneficial to people with newly diagnosed HIV (particularly those needing medical care), the public at large, and medical providers. In areas where the projects took place, we observed that a high percentage of people with newly diagnosed HIV was linked to care and that a similarly high proportion achieved viral load suppression, both of which were likely to improve the quality and length of the lives of those with HIV. In addition, the high proportion of people with viral load suppression that we observed was beneficial to the public, because lifetime HIV treatment costs and risks of transmitting HIV to others tend to be lower for people who have achieved viral load suppression than for people who have not achieved viral load suppression.<sup>16,17,27,28</sup> Moreover, both the improved health outcomes of patients and the reduced need for medical office staff members to search for those with HIV who may have moved, died, or engaged in care elsewhere were beneficial to medical providers. During the demonstration projects, health department staff members (eg, disease intervention specialists, navigators, facilitators, or bridge workers) located out-of-care patients, interviewed them, and linked them to medical care and other services

known to improve the ability to stay in care and to adhere to medication.<sup>2,5,6,29,30</sup> Depending on local policy and laws, health departments also provided helpful information about patients to their medical providers, who otherwise would not have had access to such information.<sup>6,31</sup>

Our results also suggest that health departments benefited from these demonstration projects. During the project, surveillance staff members reported more accurate, up-to-date surveillance data than before the project was conducted, which likely resulted in more accurate determinations of whether people had been linked to care, improved monitoring of HIV and its characteristics (eg, demographic characteristics and risk information, linkage status), and more efficient and effective HIV prevention program activities, ultimately leading to better use of public health HIV prevention funds.

Nevertheless, to optimize linkage-to-care activities such as those in these demonstration projects and to minimize possible harm (eg, breaches of confidentiality, discrimination), active support from members of the HIV community is critical.<sup>5,30,32</sup> It is noteworthy that all 5 health departments in our study reported that the demonstration projects resulted in improved collaboration and coordination among surveillance staff members, HIV prevention program staff members, and medical providers. Trusting relationships are needed among health departments, medical providers, communities, and people with HIV who need assistance with linkage to care. Nongovernmental organizations (eg, HIV service organizations, community-based organizations, Federally Qualified Health Centers) that work with health departments may also play an important role in linkage-to-care activities. Ideally, all of these stakeholders in the linkage-to-care process should be part of HIV prevention program planning, implementation, and monitoring and evaluation, and they should adhere to CDC funding requirements (eg, security and confidentiality requirements<sup>22</sup>), state laws, local policies, and the Health Insurance Portability and Accountability Act.

HIV prevention program-funded nonresearch demonstration projects have value in their ability to positively and promptly influence the day-to-day practice of public health. The fact that the 5 demonstration projects in our study sustained these activities after CDC funding ended is a testament to the benefits perceived by those working in this setting. However, research is needed to inform and improve the practice of public health so that it is as evidence based and effective as possible. Specifically, research is needed to better understand how to most efficiently and effectively link people to care, retain them in care, and reengage those who were previously in care but have since fallen out of care.<sup>18,29,33,34</sup> Indeed, 2 recent systematic reviews about engagement in HIV care identified only 4 evidence-based interventions aimed at reengaging people in care and considered this "a paucity of data"<sup>33</sup> and a "glaring research gap."<sup>34</sup> Also, more research is needed into the use of surveillance and other types of data for engagement in care to better understand metrics that measure and track linkage to care,

retention in care, and reengagement in care and to more effectively prioritize work on lists of people who are presumed to be out of care.

### Limitations

Our findings had several limitations. First, the outcomes of these demonstration projects are not generalizable to all health departments, because the health departments were not selected randomly and their projects did not use a standardized protocol. Nevertheless, these nonresearch demonstration projects provided important HIV prevention programmatic information that may be disseminated among and potentially relevant to other health departments. Because the HIV prevention program staff members who are responsible for HIV prevention program-led demonstration projects are also usually the same staff members who handle the local policy and practice of public health, local policy and practice can be readily changed when projects such as those in our study are deemed successful or potentially useful.

Second, in reporting results, we used laboratory data as a proxy for linkage-to-care status. However, laboratory results often do not accurately reflect a person's linkage-to-care status.<sup>35,36</sup> This potential for inaccuracy may be partially mitigated by the fact that historically, laboratory data were not always reported and entered into the HIV surveillance database in a timely manner, possibly reducing their value as a proxy. Yet, the number of health departments that report complete laboratory data to CDC has increased in recent years,<sup>10,37,38</sup> and all 5 health departments in our study have provided complete and timely HIV laboratory surveillance data to CDC since 2012<sup>37</sup> or 2013.<sup>38</sup> Ultimately, although the use of laboratory data as a proxy for linkage to care was not ideal, supplementation of these data with information from other sources (eg, electronic medical records) has been shown to improve the accuracy of estimates of linkage-to-care status.<sup>15,39,40</sup>

Third, detailed data related to routine HIV prevention and demonstration project activities needed to calculate denominators were not reported by or collected from all involved health departments. Therefore, the actual differences between routine and demonstration project linkage-to-care percentages may not be as large as we observed, particularly if the exclusion criteria used for routine linkage-to-care activity calculations were less stringent than those used for demonstration project linkage-to-care activity calculations. However, our choice of exclusion criteria (and, thus, denominators) for assessing the demonstration projects allowed us to focus on what we considered the most important metric, which was the linkage to care of people once they were identified and reached.

Finally, we were unable to attribute the linkage-to-care results for the 5 health departments in our study directly or solely to the demonstration projects involving the use of HIV surveillance data. Indeed, we did not obtain or compare details of how the various health departments used

surveillance data to link people to care, nor did we obtain or compare details of the routine linkage-to-care activities used by the other health departments. However, we were able to compare the linkage-to-care results of the 5 health departments when they used HIV surveillance data (89%) with the results of the same 5 departments during a similar period when they instead used routine linkage-to-care activities (66%), and the difference in linkage to care was substantial.

### Practice Implications

The HIV demonstration projects evaluated in this study are the first in which the CDC FOA for comprehensive HIV prevention program activities was used to promote the use of HIV surveillance data for linkage to care. The experience of these demonstration projects informed the planning of a new FOA (PS18-1802)<sup>41</sup> that combines surveillance and HIV prevention program FOAs into a single FOA, to help improve patient outcomes with the use of HIV surveillance data for linkage-to-care activities.

These demonstration projects, in which HIV surveillance data were used to link people with newly diagnosed HIV to care, resulted in substantial clinical and public health benefits, so much so that the projects remained active even after CDC funding ended. The projects also highlighted the value of medical providers and laboratories reporting complete and up-to-date information to health department surveillance systems. For future HIV prevention programs that use HIV surveillance data for linkage to care to have maximum impact on HIV, collaboration among people with HIV, medical providers, community-based organizations, and public health practitioners will be critical.

### Acknowledgments

The authors appreciate the dedication of the CDC Project Officers and local health department staff members who worked on these HIV demonstration projects in Alaska, Hawaii, Maryland, Minnesota, and Washington.

### Disclaimer

The findings and conclusions in this article are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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