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## Addressing the Challenges of the HIV Continuum of Care in High Prevalence Cities in the United States

**Alan E. Greenberg, MD, MPH<sup>1,2</sup>, David W. Purcell, JD, PhD<sup>3</sup>, Christopher M. Gordon, PhD<sup>4</sup>, Rebecca J. Barasky, MPH<sup>1,2</sup>, and Carlos del Rio, MD<sup>5,6</sup>**

Alan E. Greenberg: aeg1@gwu.edu; David W. Purcell: dpurcell@cdc.gov; Christopher M. Gordon: cgordon1@mail.nih.gov; Rebecca J. Barasky: rbarasky@gwu.edu; Carlos del Rio: cdelrio@emory.edu

<sup>1</sup>Department of Epidemiology and Biostatistics, Milken Institute School of Public Health, George Washington University, Washington, DC

<sup>2</sup>District of Columbia Developmental Center for AIDS Research, Washington, DC

<sup>3</sup>Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, Atlanta, GA

<sup>4</sup>Division of AIDS Research, National Institute of Mental Health, Bethesda, MD

<sup>5</sup>Hubert Department of Global Health, Rollins School of Public Health of Emory University, Atlanta, GA

<sup>6</sup>Emory Center for AIDS Research, Atlanta, GA

### Introduction

The overarching theme of this supplemental issue of the Journal of Acquired Immune Deficiency Syndrome (JAIDS) is addressing the challenges of the HIV continuum of care in high-prevalence cities in the United States. The supplement features ten articles describing research projects conducted by National Institutes of Health (NIH)-supported Centers for AIDS Research (CFAR) and AIDS Prevention Center (APC) academic investigators, with their complementary biomedical and behavioral expertise, working largely in collaboration with their local public health departments. This supplemental issue describes the second series of studies to emerge from an NIH-funded initiative designed to increase collaborations among the CFARs, APCs and local public health departments to inform and enhance outcomes in the HIV care continuum in settings where evidence-based practices are urgently needed.

This introductory article begins with a brief overview of the National HIV/AIDS Strategy (NHAS)<sup>1</sup> and the federal HIV Care Continuum Initiative (CCI)<sup>2</sup>, and a summary of current CDC programs established to address the NHAS and the HIV continuum of care. A summary of the current status of HIV care continuum research in the United States is

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Correspondence to: Alan E. Greenberg, MD, MPH, Department of Epidemiology and Biostatistics, Milken Institute School of Public Health, 950 New Hampshire Ave, NW, 5<sup>th</sup> floor, George Washington University, Washington, DC 20052 (aeg1@gwu.edu).

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presented, followed by an overview of the NIH-supported CFAR/APC Working Group on the HIV Continuum of Care<sup>3</sup> that was created to address research gaps in this scientific arena. Lastly, a synthesis of the ten articles written by members of the Working Group that comprise this supplement is provided.

## National HIV/AIDS Strategy and the HIV Care Continuum Initiative

The National HIV/AIDS Strategy, released by President Obama in July 2010, ushered in a new era with important changes in how HIV research, prevention, and care are implemented in the United States.<sup>1</sup> It focuses on decreasing new HIV infections, improving access to and outcomes from HIV care, reducing disparities, and increasing coordination across the various levels of government responsible for funding research, prevention, and care. The goals of NHAS were reinforced by the HIV Care Continuum Initiative (CCI), launched by Executive Order in July 2013.<sup>2</sup> The CCI directs federal agencies to enhance their efforts to improve outcomes across the continuum of care, namely by reducing the number of people with HIV who are undiagnosed, linking diagnosed persons into care, retaining HIV-positive persons in care so that they can obtain the benefits of HIV medications, and helping them to achieve viral suppression. Of note, both the NHAS and the CCI were introduced in the context of dramatic scientific advances related to HIV prevention, rapid changes in health care with the implementation of the Affordable Care Act, and shrinking public health budgets for HIV prevention.

After the CCI was announced, an Interagency HIV CCI Federal Working Group was formed that released a report in 2013 that included five recommended action steps that federal agencies were to consider and address if within their missions.<sup>4</sup> These five recommendations were to: 1) support, implement, and assess innovative models to more effectively deliver care along the care continuum, 2) tackle misconceptions, stigma, and discrimination to break down barriers to care, 3) strengthen data collection, coordination, and use of data to improve health outcomes and monitor use of federal resources, 4) prioritize and promote research to fill gaps in knowledge along the care continuum, and 5) provide information, resources, and technical assistance to strengthen the delivery of services along the care continuum, particularly at state and local levels.<sup>4</sup> The Office of National AIDS Policy (ONAP) released a report in December 2014 that provides a comprehensive overview of what federal agencies have been doing to achieve NHAS goals and improve outcomes along the HIV continuum of care.<sup>5</sup> The report provides an illuminating snapshot of how a broad range of federal agencies have acted to achieve the goals and vision of NHAS, and it shows progress along the continuum of care but indicates that much work remains to be done.<sup>5</sup>

## Summary of Current of CDC Programs on the HIV Continuum of Care

For illustrative purposes we provide an overview of some of the recent activities implemented by the Centers for Disease Control and Prevention (CDC), in response to the NHAS and particularly the CCI.

For HIV prevention, CDC directly funds all state health departments in the United States, eight large-city health departments, and a handful of territorial or other special health departments. The CDC also directly funds over 100 community-based organizations

(CBOs), and provides indirect support to even more CBOs through health department funding. This funding covers basic public health activities such as HIV surveillance (health departments only), and HIV programs such as HIV testing, linkage to care, and behavioral interventions to reduce risk, enhance linkage to and engagement in care, and improve adherence to HIV treatment. One important shift in HIV prevention since 2010 is that surveillance and programmatic activities, once very separate domains, are increasingly becoming linked and interdependent as surveillance data are being used for programmatic purposes at both the individual level (for patient tracking through the care continuum) and the jurisdictional level (for monitoring of outcomes along the care continuum).<sup>6</sup> Recent funding announcements have supported this linkage and have also directed grantees to focus on highest impact activities, learn how to bill for services now covered by the ACA such as HIV testing, implement systems that allow complete reporting of surveillance data, including HIV care indicators, and explore how to share those data safely for program use.

Immediately after NHAS was announced, CDC began, with support from numerous federal partners, the first of three demonstration projects with health departments to design and implement programs to best meet NHAS goals and accelerate progress along the continuum of care. The first project, ECHPP (Enhanced Comprehensive HIV Prevention Planning), involved the implementation of a wide range of high impact HIV prevention activities in the 12 cities with the most cases of AIDS.<sup>7</sup> As described below, NIH also provided funding to researchers in most of the ECHPP cities to conduct research in conjunction with health departments to support the goals of ECHPP and NHAS.<sup>8</sup> In 2012, the second project, Care and Prevention in the United States (CAPUS) was implemented in eight states including six southern states. This project focuses on improving outcomes across the continuum of care as well as addressing the social determinants of health that most directly affect continuum outcomes in each jurisdiction.<sup>9</sup> In 2014, the third project, Partnerships for Care (P4C) was implemented with funding going to four health departments from CDC and to up to six community health centers in each jurisdiction (funded by HRSA's Bureau of Primary Health Care). There are over 100 service sites involved in P4C and the goal is to increase provision of routine HIV screening and HIV prevention and care services in health centers in areas adversely affected by HIV.<sup>10</sup>

In addition to the high visibility demonstration projects, CDC has research, programmatic, and surveillance efforts to improve outcomes along the continuum of care. CDC launched a website on the "data to care" or D2C strategy of using surveillance data for programmatic purposes to follow up on individuals shown to be out of care. This tool is one of many identified by federal agencies that support NHAS and the CCI.<sup>5</sup> In 2014, CDC funded the Cooperative Re-Engagement Controlled Trial (CoRECT) to test the data to care strategy of using surveillance and clinic data to identify and re-engage people out of HIV care. CDC HIV surveillance staff and grantees have worked on improving completeness of lab data reporting (key for monitoring continuum of care outcomes) and provided technical assistance on how to calculate the continuum of care using CDC guidance for local analyses. CDC has also required that funding for some activities is contingent on state collection and submission of data necessary to calculate the care continuum. In September 2014, CDC released the first "State HIV Prevention Progress Report" which provides data, where available, across all states and the District of Columbia for six indicators that measure

outcomes across the continuum of care.<sup>11</sup> This report showed that no state was in the bottom or top quartile on all indicators, and it highlights the fact that national goals cannot be met without closing the gaps between states. CDC launched two communication campaigns in 2014. “HIV Treatment Works” targets HIV-positive persons to try to improve outcomes along the continuum of care while “Start Talking, Stop HIV” is a campaign targeted to all gay and bisexual men urging communication with partners and understanding of the many new prevention options available today. Finally, CDC expanded its Compendium of Evidence-Based Interventions and Best Practices for HIV Prevention to include interventions to improve adherence to care (2012) and interventions to improve linkage to and retention in care (2014).<sup>12</sup> The activities covered here highlight the focus on continuum of care activities at just one agency, but they mirror what has occurred at many federal agencies to respond to the groundbreaking National HIV/AIDS Strategy and the Care Continuum Initiative.

### **Current Status of HIV Continuum of Care Research in the United States**

Providing optimal care for HIV-infected individuals and improving outcomes by decreasing morbidity and mortality from HIV has always been a major goal of care since the early years of the HIV epidemic. In August of 1990 the US Congress passed the groundbreaking Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.<sup>13</sup> At the time the legislation was passed, more than 150,000 AIDS cases had been reported in the US, more than 100,000 had died and antiretroviral therapy as we know it today was not available. The CARE Act is a unique program that, as payer of last resort, has helped level the playing field by making access to care available to those who are uninsured or underinsured. The CARE Act has undergone major changes since then and has grown to a program that provides care to more than 536,000 HIV-infected individuals with a budget of over \$2.3 billion dollars per year in FY14. More recently, improving virologic outcomes of those in care has become a major goal of the program.

In 2007, Cheever et al published a paper that highlighted the fact that engagement in HIV care falls in a continuum that begins with the HIV infected individual unaware of their status and extends to the individual who is fully engaged in care and virologically suppressed.<sup>14</sup> With the results of HPTN 052<sup>15</sup> and the realization that achievement of virologic suppression of those infected with HIV leads to a dramatic reduction of transmission, the era of “treatment as prevention” began and a major focus of both care and prevention programs has become improving access to care and virologic suppression. However, it was soon realized that population-wide virologic suppression is not as simple as it seems: that in both developed and developing countries there is substantial patient loss at each step of the care continuum from HIV diagnosis to linkage to care, retention in care, initiation of antiretroviral therapy and virologic suppression; and that, despite the large amount of resources that are dedicated to HIV prevention and care in the U.S., less than 30% of HIV infected persons are believed to be virologically suppressed.<sup>16</sup> Clearly understanding the HIV care continuum and improving it through the implementation of evidence-based interventions is a major priority if we are to achieve the NHAS goal of an “AIDS-free generation”.

In the past year, many efforts have also been made at the global level to achieve better outcomes. UNAIDS has recently set ambitious targets in their “90-90-90” initiative stating that by 2020, 90% of all people living with HIV will know their HIV status, 90% of those diagnosed will be on antiretroviral therapy and 90% of those on therapy will have viral suppression.<sup>17</sup> This is clearly an aspirational goal but even when 90% of HIV infections are diagnosed, 90% are engaged in care and 90% of treated individuals are virologically suppressed there are still about 34% of HIV-infected individuals who remain viremic and potentially infectious to others.<sup>18</sup> Understanding that improvement in any single component of the care continuum in isolation will have minimal impact on the proportion of HIV-infected individuals with an undetectable viral load is critical for program implementation to be successful at a population level.

Research focusing on the HIV care continuum has exploded in recent years. Through January 2015, a total of 655 articles are available in PubMed searching the “HIV care continuum” (362 since 2011). At major HIV conferences such as the Conference on Retroviruses and Opportunistic Infections (CROI), IDWeek and the International Conference on AIDS, HIV care continuum presentations have become common enough that sessions are now devoted to this topic. Available published research on the HIV care continuum can be classified into three major areas: 1) Descriptive/epidemiological studies; 2) Assessing and modeling the impact of interventions; and, 3) Monitoring quality of care.

Descriptive/epidemiological studies have focused on describing the care continuum in different countries and populations/subpopulations. At the national level in the U.S., the CDC has documented significant age disparities across the continuum with younger age individuals being less likely to achieve viral suppression.<sup>19</sup> This disparity is more pronounced among young black men.<sup>20</sup> Clinical outcomes including virologic suppression appear to be significantly better in integrated care settings and structured programs that minimize barriers to care such as co-pays. For example, among members of the U.S. Air Force, median CD4 count at diagnosis between 2006 – 2011 was 479 cells/uL, and there was a shorter time from diagnosis to initiation of antiretroviral therapy, with more than 88% of patients achieving virologic suppression at one year.<sup>21</sup> Similarly, the VA has reported high rates of virologic suppression with the reduction of institutional barriers to care and treatment.<sup>22</sup> An analysis of the Ryan White Program in 2011 also suggested high rates of virologic suppression among patients retained in care<sup>23</sup> but this study also reminds us that retention in care is challenging, particularly for individuals aged 13 – 34 years.

Studies assessing and modeling the impact of interventions have helped define which integrated packages of interventions will be more effective at a population level. For example, among HIV-infected persons who use drugs, screening for and treatment of underlying substance use disorders is critical.<sup>24</sup> Modeling data from Newark suggests that implementation in 2013 of a combination of interventions will lower incidence by only 16% by 2023.<sup>25</sup>

A major use of the HIV care continuum has been to monitor quality of care and provide evidence that equity in HIV care outcomes is attainable when high quality care is provided.<sup>26</sup> Except for studies to increase HIV testing uptake and adherence to antiretroviral

therapy, interventions that specifically address the care continuum through randomized controlled trials are sparse in the literature. A linkage to care intervention called ARTAS is an example<sup>27</sup>, as is a recent intervention to improve retention in care.<sup>28</sup>

As research studies of interventions to improve the care continuum are implemented, it is important that we recognize that issues such as stigma, discrimination, poverty, unstable housing, co-pays, etc. will all affect outcomes and thus social determinants of disease should be front and center of such interventions. Therefore studies evaluating the use of peer health navigators and contingency management to improve outcomes such as NIDA CTN study 049 (NCT01612169) are quite timely. Finally, the Affordable Care Act offers an opportunity to study the impact of a major change in health policy in HIV care outcomes.

## CFAR/APC Working Group on the HIV Continuum of Care

The CFAR/APC HIV Continuum of Care Working Group, formerly known as the CFAR ECHPP Working Group, was founded in 2011 to promote and conduct HIV implementation science research by academic investigators in collaboration with their local Departments of Health.<sup>3</sup> An initial round of funding (ECHPP-1) was awarded in September 2011 to support CFAR investigators in the nine highest AIDS prevalence cities in the U.S. (Atlanta, Chicago, Houston, Los Angeles, Miami, New York City, Philadelphia, San Francisco and Washington, DC) to conduct research on HIV prevention and care interventions in support of the CDC ECHPP initiative. In a previous supplemental issue of JAIDS published in November 2013,<sup>8</sup> results from these studies were presented on HIV testing,<sup>29–30</sup> linkage to care, retention and re-engagement in care, maximizing viral suppression<sup>31–33</sup>, HIV health service provision<sup>34–36</sup> and non-occupational post-exposure prophylaxis.<sup>37</sup>

In August 2012, a second round of funding (ECHPP-2) was awarded to investigators at these nine CFARs, as well as to investigators at three co-located National Institute of Mental Health (NIMH)-supported APCs in New York, San Francisco and Los Angeles. This funding was to support implementation science focused on the HIV care continuum – specifically on HIV testing, linkage to care, retention and re-engagement in care, and adherence to ARVs. A third round of funding (ECHPP-3) was awarded in summer 2013 to investigators at 10 CFARs (including six that were new to this initiative) to develop pilot interventions with their local DOHs to address the HIV continuum of care.

In addition, the NIMH Division of AIDS Research (DAR) and the National Institute of Allergy and Infectious Diseases (NIAID) Division of AIDS (DAIDS) recently issued a Program Announcement intended to address limitations in current understanding of the HIV care continuum ((PA-14-132: Accelerating Improvements in the HIV Care Continuum (R01), <http://grants.nih.gov/grants/guide/pa-files/PA-14-132.html>). Although this subset of priorities is not meant to be exhaustive, noteworthy among imperative research directions are; 1) better understanding of engagement in care in a non-linear manner, as patients re-engage in HIV care in a range of pathways, 2) better understanding and intervention development for subpopulations within the care continuum whose outcomes are particularly poor (e.g., young MSM of color), 3) addressing the relative dearth of intervention development and testing for linkage to care (compared to advancements in treatment



adherence), 4) studies of multi-level factors (e.g., including systemic and structural barriers and facilitators) that affect HIV testing, linkage, and retention in care, and 5) measurement and methodological progress to help advance accurate assessment of care continuum monitoring (e.g., especially with innovative uses of available surveillance data). The papers in this present supplement also target these areas, and may contribute to public health department approaches to enhance patient progress through the care continuum to viral load suppression.

## Synthesis of ECHPP-2 Continuum of Care Manuscripts

A synthesis of the ten manuscripts that are included in this supplemental issue of JAIDS is presented in this section, roughly grouped by the steps in the HIV continuum of care. The cities, CFAR/APC, first author and Site PI(s), and Project Aims for each project are shown in Table 1.

A retrospective cohort study was conducted in **Houston** to assess whether a routine opt-out HIV testing program coupled with linkage to HIV care services based in Emergency Departments improved parameters along the HIV continuum of care for persons previously diagnosed with HIV infection. Among more than 2,000 persons, significant improvements were demonstrated when pre- and post-visit rates were compared for linkage to care, retention in care and viral suppression.<sup>38</sup>

In **New York City**, qualitative interviews were conducted with 80 HIV-infected persons in populations identified as inadequately engaged in HIV medical care: African immigrants, previously incarcerated adults, transgender women and young MSM. Barriers and facilitators to care were identified in three principal domains: health care and system factors, such as the patient-provider relationship and social service agencies; social factors, including family and social support, stigma, substance abuse, sexual orientation, gender identity and incarceration; and individual level factors such as mental illness, substance use and resilience.<sup>39</sup>

In **Chicago**, a clinic-based approach for assessing retention in care (based on number of patient visits) for about 2,500 patients seen at Cook County's HIV clinic in 2011 was compared with varying surveillance-based approaches (based on HIV laboratory reports to the Chicago Department of Public Health). The authors found that clinic- and surveillance-based databases can be securely matched and compared for large numbers of patients, and that a surveillance definition of having two or more HIV viral loads and/or CD4 counts from the same laboratory more than 90 days apart had the best balance of sensitivity and specificity when compared with clinic-based definitions.<sup>40</sup>

Sixteen key stakeholder discussions, a "national think tank", and a local community consultation were held in **San Francisco** to gain insights into community acceptance and perspectives on the use of surveillance data by departments of public health to improve linkage, retention and re-engagement rates for HIV-infected persons in care. The results supported the use of multiple approaches if key stakeholders were involved early in the development of such programs and throughout their implementation. Multiple strategies, each with their own benefits and drawbacks, were deemed acceptable including provider-

mediated outreach, electronic data linkages, and direct outreach by trained patient navigators.<sup>41</sup>

In **Philadelphia**, investigators examined whether there were individual and community-level factors associated with poor rates of retention in care and viral suppression in geographic areas that had been previously found to have low rates of these parameters. The authors found significant associations between residence in these “hotspots” and factors such as gender, economic deprivation, travel distance to medical care and pharmacies, and access to public transit.<sup>42</sup>

In **Washington, DC**, 169 HIV outpatients were surveyed regarding their care-seeking behaviors and matched to both clinic-based records and the DC Department of Health surveillance registry. Using HRSA definitions, 68% of patients were classified as in care, 20% as receiving sporadic care, and 12% as out of care. However, of the 21 patients defined as out of care, 52% believed they were fully engaged in care, 71% had a non-HIV medical visit in the past year, and 90% reported they were on antiretroviral therapy. Thus, patient perceptions of their HIV care status differed from clinic- and surveillance-based definitions.<sup>43</sup>

In **San Francisco**, clinic-based outreach and matching with the local Department of Public Health HIV surveillance registry were used to assess how these could be used in a complementary manner to assess whether HIV patients who were late for HIV primary care at a large public clinic were truly lost to care. Of a 10% sample of patients who were believed to be out of care, 63% were found to be in-care by more intensive clinic-based outreach, while of those classified by the local HIV surveillance registry as out of care, 52% were found by clinic-based tracking to be in-care. Thus, clinic-based tracking and surveillance registry matching substantially reduced an estimate of the cumulative incidence of those lost to care over three years based on patient visit information alone.<sup>44</sup>

In-person interviews were conducted with 444 HIV-infected outpatients in **Miami** to explore whether individual and “systemic” barriers were associated with clinic attendance. Non-clinic attenders were found to have significantly higher viral loads and lower CD4 counts than regular and irregular attenders; significantly greater individual barriers to care (depression, quality of life, etc.) compared with regular attenders; and significantly greater systemic barriers including decreased communication with their physicians and increased transportation barriers than regular and irregular attenders. Importantly, an increased total number of barriers was found to be significantly associated with reduced rates of viral suppression.<sup>45</sup>

In **Atlanta**, five focus group discussions were conducted among 35 gay and bisexual men to assess whether a dyadic couples-based approach to HIV care could affect positive outcomes along the HIV care continuum. Participants indicated that the dyadic approach could provide emotional, informational and “instrumental” (i.e., accompaniment, financial assistance, reminders) support that could contribute to improved engagement in HIV care and antiretroviral adherence.<sup>46</sup>



Lastly, a randomized pilot study was conducted In **Los Angeles** among 50 HIV-infected patients to assess the impact of self-monitoring of antiretroviral medication adherence, mental health, substance use and sexual risk behaviors using smartphone technology compared with bi-weekly web-based surveys. The authors conclude that self-monitoring of various HIV-related parameters is technically feasible and potentially efficacious, and that further research of this approach is warranted.<sup>47</sup>

## Summary

In summary, addressing the challenges of the HIV care continuum is critical so that the goals of the National HIV/AIDS Strategy can be achieved. CDC is working closely with federal partners, public health departments and communities throughout the U.S. on multiple surveillance, programmatic and research initiatives to inform and improve outcomes along the HIV care continuum. Currently, a large number of research projects are being conducted to describe the care continuum in various populations, assess and model the impact of interventions, and monitor the quality of care. To contribute to this knowledge base, NIH is working with its academic partners to support research that will inform the optimization of HIV treatment and prevention programs. As part of this focus, the CFAR/APC HIV Continuum of Care Working Group was formed to encourage communication between academic investigators and their local departments of health, and to support joint research initiatives that are both timely and relevant to their own cities and environments. In addition, the results presented in this supplement may have implications for jurisdictions beyond those in which the studies were conducted.

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**Table 1**

Project City, CFAR/APC, First Author/Site PI and Aims

City	CFAR/APC	First Author/Site PI	Project Aims
Atlanta	Emory	Goldenberg/Stephenson	<ul style="list-style-type: none"> <li>Examine MSM's perceptions of how a dyadic approach towards the HIV continuum of care could impact partner support for engagement in care and HAART adherence</li> </ul>
Chicago	Chicago D-CFAR	Lubelchek	<ul style="list-style-type: none"> <li>Compare clinic visit vs. surveillance lab-based measures of retention-in-care to assess which surveillance-based indicators most accurately reflect continuous, outpatient HIV care</li> </ul>
Houston	Baylor College of Medicine/UT Health	Flash/Giordano	<ul style="list-style-type: none"> <li>Determine whether large-scale HIV testing and a robust linkage to care program in the emergency room setting improves outcomes in previously diagnosed patients</li> </ul>
Los Angeles	University of California Los Angeles	Swendeman	<ul style="list-style-type: none"> <li>Conduct a pilot study of self-monitoring daily by smartphone and bi-weekly by web-based survey to examine perceived benefits and elaborate a theoretical model for the potential efficacy of self-management among persons living with HIV</li> </ul>
Miami	University of Miami	Wawrzyniak/Rodriguez and Metsch	<ul style="list-style-type: none"> <li>Examine how individual and systemic barriers are associated with retention in care and virologic suppression among outpatients from a large HIV clinic</li> </ul>
New York City	Albert Einstein /Montefiore	Remien/Bauman and Remien	<ul style="list-style-type: none"> <li>Conduct a qualitative study exploring system, social, and individual barriers to and facilitators of engagement in HIV care among African immigrants, previously incarcerated adults, young MSM, and transgender women</li> </ul>
Philadelphia	Penn	Eberhart/Metzger	<ul style="list-style-type: none"> <li>Examine whether there are individual and community-level factors associated with poor rates of retention in care and viral suppression in geographic areas previously found to have low rates of these parameters</li> </ul>
San Francisco	University of California San Francisco	Evans/Charlebois and Morin	<ul style="list-style-type: none"> <li>Gain insights into community acceptance and perspectives on the use of surveillance data by departments of public health to improve linkage, retention and re-engagement rates for HIV-infected persons</li> </ul>
San Francisco	University of California San Francisco	Christopoulos/Charlebois and Morin	<ul style="list-style-type: none"> <li>Assess the contributions of clinic-based outreach and surveillance laboratory data in ascertaining care</li> </ul>

City	CFAR/APC	First Author/Site PI	Project Aims
			outcomes for patients putatively lost to clinic follow up
Washington, DC	District of Columbia D-CFAR	Castel	<ul style="list-style-type: none"><li>• Compare self-reported care status and perceptions regarding engagement in care with data obtained from HIV surveillance and medical records</li></ul>

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