

# Barriers and Facilitators of Linkage to HIV Primary Care in New York City

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**Abstract:** One in 5 people living with HIV are unaware of their status; they account for an estimated 51% of new infections. HIV transmission can be reduced through a “Test and Treat” strategy, which can decrease both viral load and risk behaviors. However, linkage of newly diagnosed HIV-positive persons to care has proved challenging. We report quantitative and qualitative data on linkage to care from HIV testing sites that partnered with the New York City Department of Health and Mental Hygiene to implement “The Bronx Knows” (TBK), an initiative that tested 607,570 residents over 3 years. During TBK, partner agencies reported the aggregate number of HIV tests conducted, the number of confirmed positives (overall and new), and the number of confirmed positives linked to medical care. We conducted qualitative interviews with directors of 24 of 30 TBK HIV testing agencies to identify linkage barriers and selected 9 for case studies. Barriers to linkage fell into 3 domains: (1) health care system factors (long wait for provider appointments, requirement of a positive confirmatory test before scheduling an appointment, system navigation, and disrespect to patients); (2) social factors (HIV stigma); and (3) characteristics of risk populations (eg, mental illness, homelessness, substance use, and immigrant). Best practices for linkage included networking among community organizations, individualized care plans, team approach, comprehensive and coordinated care services, and patient peer navigation. Research and public health implications are discussed.

**Key Words:** HIV cascade, linkage to care, HIV/AIDS, HIV testing, stigma

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## INTRODUCTION

Researchers and public health officials nationally are orchestrating HIV prevention and treatment efforts around the

HIV “treatment cascade” or “continuum of care,” which identifies multiple necessary steps—HIV diagnoses; linkage, engagement, and retention in care; treatment; and adherence—to achieve viral load (VL) suppression.<sup>1</sup> The first National HIV/AIDS Strategy established targets to improve the care continuum, including a target for linkage: by 2015, linking 85% of patients within 3 months of HIV diagnosis.<sup>2</sup>

Since 2004, the New York City (NYC) Department of Health and Mental Hygiene (DOHMH) has promoted HIV testing to New York City residents.<sup>3</sup> In 2008, the DOHMH launched The Bronx Knows (TBK), a 3-year community-wide HIV testing initiative in the Bronx, NY.<sup>4</sup> Its goal was to increase voluntary testing so that all Bronx residents learned their HIV status and had access to quality care and prevention. The DOHMH partnered with Bronx hospitals, community health centers (CHCs), and community-based organizations (CBOs) to increase HIV testing and link HIV-infected individuals promptly to HIV primary care medical services. The 3-year goal was to conduct 250,000 HIV tests, based on NYC Community Health Survey data of the estimated number of Bronx residents aged  $\geq 18$  years never tested for HIV. As previously reported, at the end of TBK, partners had more than doubled the initiative’s goal by conducting 607,570 HIV tests.<sup>5</sup> Of more than 1700 persons newly diagnosed with HIV as a result of testing by TBK partners during the initiative, 76% were reported to have been linked to medical care.

Analysis of HIV surveillance data demonstrated that, in NYC, timely linkage to care (within 90 days of HIV diagnosis) for persons newly diagnosed with HIV improved from 59% in 2007 to 69% by 2011.<sup>4,6</sup> Although there has been significant recent improvement in citywide linkage rates, the current rate remains below the National HIV/AIDS Strategy goal of 85% for 2015.

## METHODS

As part of its strategy to reach the linkage goal set out by the National HIV/AIDS Strategy, the DOHMH collaborated with the Preventive Intervention Research Center and the Center for AIDS Research at the Albert Einstein College of Medicine to conduct a qualitative study of barriers and facilitators of linking HIV-positive persons to medical care. The DOHMH conducted a formative analysis of linkage rates among TBK sites to inform the design of the qualitative study. The institutional review board of the NYC DOHMH approved the formative analysis and the institutional review board of the Albert Einstein College

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of Medicine/Montefiore Medical Center reviewed the qualitative study and granted it exempt status.

### Formative Analysis

Relationships established with TBK community partners enabled DOHMH to conduct formative research for the design of the qualitative study of linkage practices by community providers. We used NYC HIV surveillance data to estimate linkage rates by facility type among TBK partners, which included all the major agencies, both clinical and nonclinical, which link HIV-positive clients to medical care in the Bronx.

As a first step, TBK partner agencies were matched to reporting facilities within the HIV Surveillance Registry. New York state requires named reporting of all diagnoses of HIV and AIDS; all HIV-related illness; all positive Western Blot (WB) tests for HIV antibody; all viral load (VL) and CD4 values; and all HIV genotypes.<sup>7-10</sup> The NYC Surveillance Registry (the Registry) is continuously updated with new, deduplicated diagnoses and laboratory results for persons living with HIV/AIDS.

Once TBK facilities were identified in the Registry, we categorized them by facility type (hospital, CHC, or CBO). We then identified the number of new diagnoses made by each partner during the TBK testing initiative (April 1, 2008–March 31, 2011) and estimated linkage-to-care rates among persons newly diagnosed with HIV within 3 and 12 months of diagnosis by facility type during this time period. Per NYC’s standard surveillance definition, successful linkage to HIV medical care was based on a reported CD4 count or HIV VL for a patient within 3 or 12 months of diagnosis, following a 7-day lag from the date of diagnostic WB. The 7-day lag excludes CD4 and VL testing likely performed as part of the initial HIV diagnostic workup and, thus, not indicative of entry into care.

### Main Study

The qualitative study had 2 phases. The goal of phase I was to identify barriers and facilitators of linkage to care through in-depth interviews with key informants from all 30 organizations that administered HIV tests at TBK sites, of which there were more than 100. We identified informants who could best report about linkage-to-care practices in their organization, typically medical directors or directors of the HIV testing program. The DOHMH contacted the informants to encourage study participation; Einstein researchers successfully interviewed 80% (24/30). The interview guide focused on operational and logistic linkage practices and included (1) definition of linkage to care, (2) site procedures for linkage, (3) barriers and facilitators of linkage, (4) differences by subpopulations, and (5) recommendations for improving linkage. Interviews lasted 30–90 minutes and were conducted over the telephone by trained masters/doctoral-level interviewers. Interviews were audiotaped; recordings were used to assure the accuracy of field notes.

In phase II, we conducted case studies<sup>11</sup> of organizations whose practices resulted in high linkage-to-care rates. The formative analysis showed linkage rates differed by facility type (hospitals, CHCs, and CBOs). Sites from each

type were chosen to capture the challenges and successes for linkage unique to each category. After eliminating sites with <10 new HIV-positive cases per year, DOHMH used the formative data set to identify the 3 CBOs, 3 hospitals, and 3 CHCs with the highest linkage rates. All 9 sites agreed to participate; data were collected through audiotaped face-to-face interviews with up to 6 personnel per site and from site observation.

Data analysis was conducted using an inductive, team-based approach<sup>12</sup> to identify themes most relevant to linkage problems and solutions. Field notes on each organization were analyzed by 5 team members through close readings of the text for emergent categories or themes, labeling and assigning relevant text segments to emergent themes, and developing memos. We created matrices summarizing the differences and similarities in themes by site type. Following common practice in qualitative research, we iteratively consulted the literature to interpret results and make sense of findings.<sup>13</sup> Data from the interviews and case studies were integrated to identify facilitators of linkage to care.

## RESULTS

### Formative Analysis

The match to the HIV Registry showed that TBK agencies identified 1262 new HIV diagnoses during TBK. Most newly diagnosed persons identified by TBK partner agencies were linked to medical care during the first 3 months (69.9%) (Table 1). Overall linkage rates rose to 84.3% by 12 months after HIV diagnosis. Hospitals and CHCs had significantly higher rates of linkage than CBOs. Within facility type, linkage rates at hospitals and CHCs significantly improved between 3 and 12 months. In contrast, there was no significant increase in linkage rates between 3 and 12 months at CBOs.

### Qualitative Results

First, we describe variations among sites in their definition of linkage to care. Then, we summarize the barriers

**TABLE 1.** Linkage to Care of Persons Newly Diagnosed With HIV by TBK Partner Agency, Overall and by Facility Type Category

All Bronx Knows Partners	Newly Diagnosed With HIV (N = 1262)	
	% (N)	P
Linked to care within 3 months	69.9 (869)	—
Linked to care within 12 months	84.3 (1048)	—
Linkage within 3 months		
Hospitals	71.3 (677)*	<0.0001
Community health centers	69.2 (175)†	0.0005
Community-based organizations	41.5 (17)‡	Reference
Linkage within 12 months		
Hospitals	86.0 (816)*	<0.0001
Community health centers	84.2 (213)†	<0.0001
Community-based organizations	46.3 (19)‡	Reference

\*Hospitals’ linkage—3 to 12 months: *P* < 0.0001.

†CHCs’ linkage—3 to 12 months: *P* < 0.0001.

‡CBOs’ linkage—3 to 12 months: *P* = 0.65.

to linkage, which clustered into 3 domains: the health care system being difficult to navigate and unwelcoming; social factors, particularly HIV stigma; and characteristics of risk populations. Finally, we identify strategies informants recommended to improve linkage to care.

## Definition of Linkage

All linkage-to-care definitions required completion of 1 or more face-to-face appointments by a newly diagnosed HIV-positive individual with an HIV care physician. Definitions differed on number of visits, content of the visit, and time to visit. About half of informants said linkage was complete after 1 visit, and the rest required 2 visits; this did not vary by site type. One third said that linkage must include laboratory tests (eg, CD4 and VL) and providing results. Most asserted that linkage should occur as soon as possible, but only 3 specified a time period (same day as the test, within 1 month, and within 4–6 weeks).

## Barriers to Linkage

### Health Care System

Many linkage barriers were rooted in the health care system, specifically its complexity, delays intrinsic to care provision, and lack of patient friendliness.

#### Complexity

For those newly diagnosed with HIV/AIDS, accessing health care is arduous. Most informants described the health care system as inaccessible and recounted the intricacies of insurance, the Ryan White program, funding parameters, Medicaid, and wrap-around services. Informants pointed out that there is no current list of HIV primary care providers in New York, and an interactive Web site designed to provide this information is challenging to use. Several informants said care coordination (CC) was an issue. People with HIV often experience cooccurring medical needs (eg, for substance use or mental health treatment); however, services are typically provided in separate locations, and communication among providers is often lacking.

#### Delays in Accessing Care

Every informant emphasized linking newly diagnosed people to HIV primary care quickly; preferably the same day they receive the preliminary positive test result. Otherwise, some people will disappear (their contact information is often incorrect), lose their courage and avoid seeing a doctor, or be paralyzed into inaction by distress or embarrassment. Many informants said that linkage is easier when HIV testing services are colocated with HIV care.<sup>14,15</sup>

Despite the firm commitment to swift linkage to care, delay was common. Informants in and out of the health care system reported shortages of HIV primary care physicians, with typical waits of 1–3 weeks for a new appointment. In addition, many clinics have weekday 9 AM–5 PM schedules, which informants reported did not always match patient needs, particularly for those who work. Almost half of informants said that not having late evening or weekend hours was a major barrier to timely linkage.

Half of the sites and most CBOs reported delayed linkage to care because HIV care sites require confirmatory test results. Typically, test sites used a rapid oral test (eg, Orasure) and a WB for the confirmatory test. Testing sites within clinical facilities reported folding confirmatory testing into an initial consultation with an onsite HIV care physician. This first visit included the blood draw, meeting with a care coordinator to identify insurance issues and social service needs, and providing data for partner notification but did not include HIV care until WB results were received. This expedited linkage process did not occur off hours; instead, patients were counseled by testing staff, and an appointment was made for the next available clinical session.

In contrast, CBOs reported that HIV primary care sites required that they have a positive confirmatory test completed before they would make an appointment for the patient with a provider. Otherwise, they claimed, tests and procedures conducted before the confirmatory test may not be reimbursed if the confirmatory test is negative. To deal with this barrier, most CBOs arranged for a local laboratory to collect blood for the confirmatory test. This posed a series of challenges—persuading patients to travel to another location for the confirmatory test, assigning staff to accompany patients to the laboratory, handling payment issues if the patient is uninsured, obtaining a Health Insurance Portability and Accountability Act (HIPAA) waiver so that the agency could obtain the test result, convincing the patient to provide contact information, making an appointment with a provider, and many times escorting the patient for their first appointment. Generally, this process took a week or 2 at best, with many opportunities for delay and loss to follow-up.

#### Lack of Patient Friendliness

Many CBO staff, particularly those who used patient escorts, reported that front-desk staff at HIV care sites were distant, rude, had “an attitude,” were unhelpful, or disrespectful. CBOs received feedback from patient escorts and their clients on how they were treated at care sites and used this information to refer patients selectively to sites that are patient friendly and, sometimes, to complain to clinical administrators.

#### Social Factors

Of 24 sites providing data, 21 identified stigma as a major barrier to linkage. Informants reported that HIV stigma caused resistance to testing, secrecy about diagnosis, fear of disclosure, social isolation, reluctance to access medical care if appearing at a clinic would identify them as HIV positive (even when clinic names were innocuous), and feeling judged by care staff for the behavior that led to HIV infection.

Accessing health care occurs in the larger social context of persistent HIV stigma, defined as devaluing people who are living with or associated with HIV and AIDS.<sup>16</sup> This may explain why HIV stigma is a barrier to uptake of treatment services in numerous settings.<sup>17</sup> Moreover, many people living with HIV experience stigma for other reasons—mental illness, substance use, participation in sex work, transgender identity, gay or lesbian sexual orientation, incarceration history, homelessness, or immigrant status. We call this “compound stigma”; HIV-positive patients with other stigmatized

statuses may be more likely to interpret routine system delays, and rude or insensitive behavior, as enacted stigma.

### Risk Populations

All HIV-positive patients are not hard to link to care. Some are difficult to link because they are hard to find and track (eg, unstably housed, homeless, and undocumented immigrants). Others have behavioral problems including people who use substances and “get clean” only to disappear when using and mentally ill persons. Informants also mentioned transgendered persons, some race/ethnic groups (Latino and West African), and men who have sex with men (MSM) and provided several reasons for their linkage problems, including toxic stress, inability to pay for health care services, low health literacy, and misinformation about the need for antiretroviral treatment regardless of symptoms. Immigrants and undocumented workers were reportedly hard to link because they fear losing their visas or deportation, they may lack English proficiency, they work long hours to support their families, and some have cultural beliefs that discourage accessing preventive care or using medication for chronic conditions. Several respondents reported that some patients lie, manipulate providers for drugs, will not go to a doctor, or do not want to be found. If a patient does not want help, they concluded, they could not force them. Provider burnout generates frustration, sometimes summarized this way: “What made them HIV positive is why they are hard to link.”

### Successful Linkage Practices

There was no 1 model of effective linkage to care or set of best practices identified that fit all organizations, population subgroups, and communities. Our data showed considerable diversity of practice; sites individualized linkage procedures based on their strengths, the specific challenges they faced, and the characteristics of their client population. Although variation was extensive, we identified clusters of linkage solutions from high-performing organizations that are “practice exemplars.” Of the 15 successful practices we identified, the first 10 were used by hospitals, CHCs, and CBOs alike.

### Patient Navigators

The most common solution for the complexity of the medical care system was system navigators, mentioned by almost all informants. There are few studies on the effectiveness of navigator models, however, Bradford et al,<sup>18</sup> demonstrated that using a navigator reduced all barriers to linkage, patient worries and stigma, and VL, and increased the amount of care patients received.

We identified 3 navigation models: (1) “classic,” 1 person navigates the health care system; (2) “temporary,”<sup>19</sup> similar to the classic navigator but only until the patient sees an HIV care provider; and (3) “partial,” multiple people provide different services. Patients tested in a medical setting typically were offered escorts to the HIV care site; often escorts were trained to educate patients about what to expect. CBOs, particularly those serving complex populations such as the homeless or previously incarcerated, provide comprehensive navigator services (eg, clothing, housing, transportation,

reminders, a patient escort to the care site, and translation). CBOs serving stigmatized populations suggested using peer navigators whose life experience can help overcome patient reluctance to enter care. The skills and training of patient navigators varied considerably, from community members trained in specific tasks to social work professionals. Navigators differ by roles and size and type of organization.

### The Team Approach

CBOs, CHCs, and hospitals all mentioned the importance of working as a team to accomplish linkage. Team models varied in their homogeneity and heterogeneity. In some smaller testing sites, everyone on the team could perform every task; at larger sites with more resources, team members had different skill sets, job titles, and responsibilities. Homogeneous teams had easy communication, high efficiency, and immediate coverage when team members were out of the office. Heterogeneous teams had access to more skills, higher levels of expertise, and more resources but required oversight and task integration to keep care seamless. Both types of teams efficiently addressed barriers to linkage.

### Relationships

Ten sites mentioned the importance of building trusting relationships both within their teams and between staff and patients. Trust was described as increasing comfort with testing and providing credibility when referring patients for linkage to care and for efficient teamwork. Forming a relationship with the patient created a psychological connection and a connection to care.

### Care Coordination

CC, also called comprehensive case management, was recommended by sites in all 3 categories to overcome delays between receiving an HIV-positive preliminary test and seeing an HIV care provider. Most described specific cases where linkage failed because patients disappeared before the linkage appointment occurred. CC works to facilitate linkage by providing other needed services to patients while they wait to access HIV care. Meeting the patient’s identified needs builds trust and enables the testing site to maintain contact with the patient during the hiatus. CC typically provided immediate, comprehensive services, especially social work/case management and was particularly useful when patients had many or urgent needs (eg, the next meal and a place to sleep that night). CC services had several features in common across sites: address both HIV and non-HIV-related needs; assess threats to linkage and make an individualized plan; identify and treat underlying problems (eg, drug use and mental illness); make specialized services available (eg, substance abuse case manager, psychiatrist); and coordinate care throughout the HIV care continuum, including engagement and adherence. Organizations varied in the specific package of services they provided. Many programs offered “linkage” case management to facilitate swift access to care and transitioned to long-term case management.<sup>15</sup> This strength-based case management model<sup>15,20–22</sup> rests in part on the social-ecological perspective that stresses the interplay of individual, relationship, community, and health care system factors. This

theoretical perspective not only underlies successful linkage practices but also improves engagement.<sup>23</sup>

### Monitor Linkage

Informants from all 3 site types reported that it was incumbent on them to monitor whether patients kept the linkage appointment. Just walking or driving people to an appointment is not enough; some clients will offer a pretext (eg, using the restroom and going out for a smoke) and disappear. However, HIPAA regulations are a barrier to confirming patient attendance; therefore, they recommended obtaining a HIPAA waiver as part of the linkage procedure.

### Minimize Stigma

Staff from all 3 site types described strategies to reduce stigma: (1) train all staff members to avoid behaviors that might stigmatize patients and deter linkage, (2) put the patient's needs first, (3) minimize the need for patients to repeat their story to different staff, (4) protect confidentiality, including linking patients to care in another neighborhood to reduce chance meetings with neighbors, (5) minimize and neutralize clinic signage, (6) use physical touch to reassure, (7) match patients to HIV care sites that understand their special needs (eg, transgendered individuals and young MSM), and (8) provide normalizing services (eg, exercise and yoga).

### Champions

Half of the sites had a champion who advocated for resources and procedures needed to assure linkage. In many instances, champions did more than advocate; they saw client problems not as personal failings but as social/structural in nature. Successful champions went above and beyond standard practices<sup>24-26</sup>; they solved problems that others tolerated, were persistent in the face of adversity, and had a reputation inside their organization for excellence and leadership.

### Staff Training

Many sites identified staff training as a key ingredient in linkage to care. In addition to training on HIV testing, staffs were trained in cultural competency and in working with special populations, such as the previously incarcerated, undocumented immigrants, MSM, and transgender women. Some went further, hiring and training staff from members of these special populations to act as peer navigators.

### Quality Assurance

Some sites were committed to improving linkage to care through monitoring their team practices and success rates, identifying performance indicators, identifying new targets and benchmarks, and implementing quality improvement activities.

### Contact Information

Informants from CBOs and hospitals emphasized collecting extensive contact information from people before they take an HIV test, verifying the address, and calling the patient's cell phone to validate it. CHCs generally had detailed information about their own patients and did not mention this; however, they suggested that patients complete a routine medical intake before the test to assure current information.

### Reduce Wait for Provider Appointments

To avoid delays in linkage, some HIV care sites added evening and weekend appointments and "open access" appointments to permit same-day linkage (eg, keep some appointments open for new patients each day and assigning rotating physicians to cover slots for new patients). Directors of HIV care sites often described the challenges they experienced in negotiating for additional care providers with care site administrators.

### Field Services

CHCs and hospitals universally lauded the Health Department's Field Services Unit within the Bureau of HIV/AIDS Prevention and Control in helping to identify patients who missed linkage appointments. Field Services is responsible for partner notification, but for HIV-positive patients who failed to link to care, they make community visits and use other creative tactics (such as monitoring online dating sites) to find the person, link them, and obtain partner data. CHCs and hospitals reported using Field Services Unit more than CBOs did.

### Organizational Networking

One third of CBOs formed organizational partnerships with HIV primary care sites. CBOs identified patient-friendly HIV care sites that provided good care through monitoring the experiences of their clients and navigators. CBOs formed an alliance with the best sites, often developing personal relationships with administrators, appointment staff, and providers. Sometimes access for clients was on a "VIP" basis: the CBO called a designated staff member at the care site who would expedite a new appointment. Although this approach had many benefits, it created delays as well, as CBOs sometimes waited for appointments with preferred providers rather than refer patients for immediate care with unknown care sites.

### Creative Confirmatory Testing

Several CBOs replaced the confirmatory blood test with a repeat rapid oral test. Not all HIV care sites accept this as a confirmatory test, but many would schedule an appointment based on it because it reduced the likelihood of a preliminary false positive.

### Mental Health Services

CBOs recommended offering immediate mental health services when an HIV test was positive. Although many patients are not surprised when told they are positive, some are overwhelmed and some deny the diagnosis. CBOs believed that providing immediate counseling removed many potential barriers to keeping a linkage appointment.

## DISCUSSION

Successful linkage was distinguished by several factors. First, it required a preventive approach that combined a sophisticated understanding of system, community, and individual barriers to linkage. The preventive approach was seen, for example, in practices such as building care referral networks, circumventing the requirement of confirmatory

blood tests, and assessing potential linkage problems. Second, it requires a comprehensive approach, addressing any barriers that may prevent a patient from accessing care. Third, it required vigilance. Regulatory requirements, innovations in testing, the changing face of the HIV epidemic, and the dynamic characteristics of affected patient populations require evolving practices that address emerging barriers and take advantage of new resources. Agencies committed to quality improvement had better linkage rates and greater efficiency. Fourth, it required human connection between patients and providers; technical solutions are important, but people make the difference in linkage success.

Organizations emphasized swift linkage to care because they cared about their clients' health. None mentioned prevention of new HIV infections as a reason for improving linkage to care. Informants (particularly clinicians) who were burned out by the strain of providing care in expanding HIV care practices were more likely to "write off" patients who did not link to care. For these practitioners, emphasizing the broader public health impact of preventing HIV transmission through Test and Treat might address these missed opportunities to reduce new HIV infections.

Ten of the 15 successful linkage practices we identified were used by all 3 site types. CBOs used state-of-the-art practices and often developed innovative approaches not found in hospitals and CHCs. We found 2 reasons for lower rates of linkage to care in CBOs compared with hospitals and CHCs. First, CBOs that had added HIV testing to their service repertoire served vulnerable populations that are hard to reach and generally were not part of the health care system. Their client populations are among the most difficult to access and serve, and even the most skilled staff will have difficulties linking active substance users, homeless people, the mentally ill, and undocumented immigrants to health care. Second, CBOs are outsiders to the health system. Even experienced, knowledgeable CBOs will face structural barriers to getting care for their clients whom those inside the system do not.

## Limitations

There are several limitations to this research. The formative analysis of surveillance data may have mismatched TBK agencies to the Registry, which would result in an underestimation of the number of new diagnoses made by TBK partners. In addition, we may have misclassified the facility type (CBO, CHC, and hospital) of some TBK partners.

The application of the 7-day lag in defining successful linkage to medical care should reduce misclassification of persons as linked to care when they only had a laboratory workup. However, it may underestimate linkage of those persons who did truly link to care within the first 7 days after HIV diagnosis and had a corresponding laboratory test but then no laboratories during the 8–91 days after diagnosis. Based on a validation study conducted by DOHMH, however, we would expect only a small percentage of successful linkages to be missed. A limitation of the qualitative research study is that we identified testing experiences as part of a large well-funded tested initiative, TBK, and included practice in 1 part of NYC; therefore, the results we report may not be generalizable. In

addition, the linkage practices we described are informants' professional opinions about what is challenging and effective in their experience; these have not been tested empirically. Furthermore, we did not interview patients themselves about their personal experiences with linkage to care; however, in a related study; we are currently interviewing patients about their experiences with HIV linkage and care engagement.

## Research Recommendations

There is little systematic evidence for the effectiveness of many of the practices we identified in this study. The practices we described were reported by informants with front-line expertise, who have been experimenting with practices, procedures, training, and policies to maximize linkage. In contrast, researchers develop interventions based on theoretical models and test them in artificial high-resource situations. Researchers should consider studies to evaluate the dynamic practices that on-the-ground experts are already using. Specifically, research is needed on the patient navigation models, strategies to reduce aversion to testing and linkage because of HIV stigma, and the best fit of different linkage practices for high-risk populations. Research is especially needed to address the structural and organizational factors that facilitate and block linkage.

## Public Health Recommendations

Local, state, and national policy initiatives may help to eliminate avoidable delays in linking HIV-positive people to care. First, requiring confirmatory test results should not remain a barrier to same-day linkage to care. Although Health Resources and Services Administration (HRSA) no longer requires a confirmatory test, HIV care sites continue to do so for financial reasons. We recommend that, in those rare instances where a patient's confirmatory test is negative, the costs of testing and physical examinations incurred after a preliminary positive test be covered through insurance or special funds so that the large majority of positive patients are not delayed unnecessarily. Second, HIV care sites should make same-day appointments available to patients testing positive for HIV. Creative scheduling can accomplish this goal without a significant increase in the number of care providers.

Third, the HIV care cascade is an invaluable tool for surveillance, research, and interventions to improve care and reduce transmission. Although the cascade is a continuum, it is generally operationalized and rewarded in discrete steps (eg, testing, linkage, and engagement). When incentives are given to organizations to accomplish 1 discrete element in the continuum, such as linkage only, they may succeed in accomplishing that element but not always in ways that solve underlying problems in the care cascade—they may simply move problems "down the continuum" from linkage to engagement. For example, some people who test positive are reluctant to link to care. To avoid the patient "disappearing," testing sites send a patient escort to accompany the person to ensure they see a physician. This accomplishes linkage in the technical sense, but it does not address the reason for the underlying reluctance to accept care. It simply

shifts the problem from the linkage stage in the continuum to engagement, for HIV care providers to solve. To achieve the end point that both optimizes individual health and reduces viral transmission—undetectable VL—we need policies and programs that solve the barriers along the way rather than hand them off.

Finally, the tensions revealed in this analysis between the public health goals and the infrastructure built into medical practice need greater effort for resolution. Medical practice limits responsibility for patient adherence to care—even in HIV, which traditionally has provided more comprehensive support services than other chronic diseases. We heard over and over that “you cannot force patients to come to care”—if they refuse there is not much the doctor can do. On its face, this seems a reasonable position. However, reducing VL not only optimizes individual health but also protects the community. Giving up on patients who do not participate in care dooms us to a future of new, yet avoidable, HIV infections. This is a community-wide challenge, one that might best be met through formal system-level collaborations among local Departments of Health, CBOs, and health care communities. CBOs often have trust and ongoing relationships with difficult-to-serve clients, and they may be valuable and effective partners with the medical establishment in linking and assuring engagement of HIV-positive patients who are out of care.

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