



C.H.A.I.N. REPORT

CHAIN 2012-1 Report

Delayed Entry into HIV Care in New York City and Tri County

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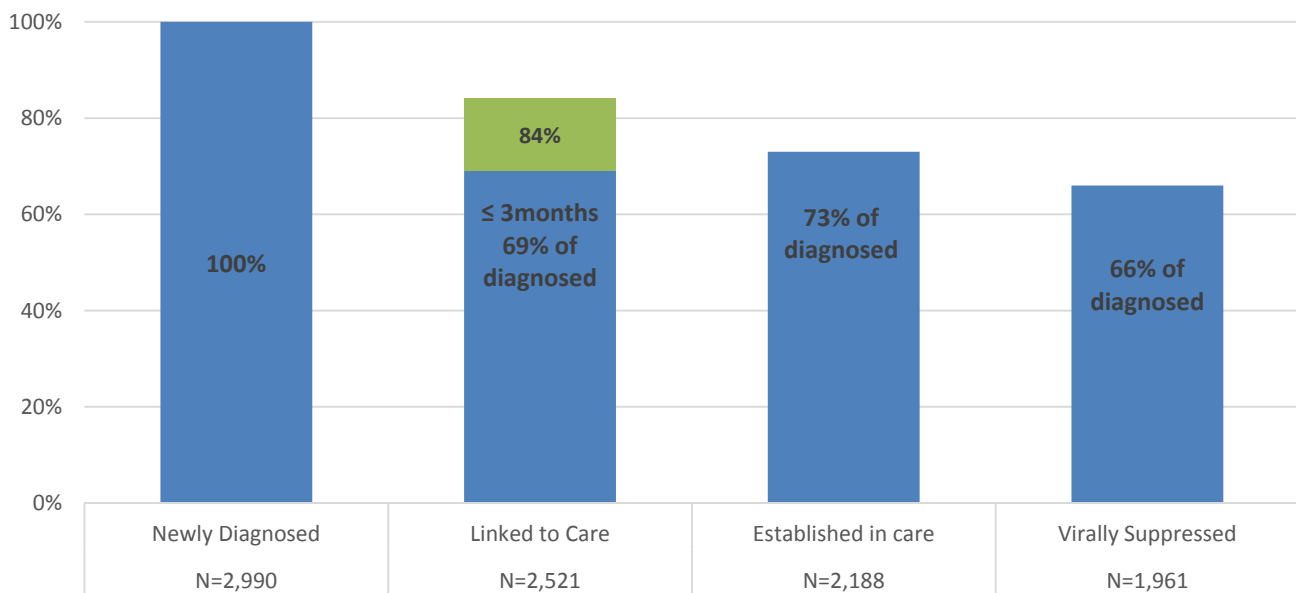
Introduction

Evidence is accumulating to suggest that a promising strategy for ending the HIV epidemic is to adopt multi-faceted approaches that combine individual-level interventions with those that address community and societal influences on risks for and health outcomes of infection (Adimora & Auerbach, 2010; Dean & Fenton, 2010; Gupta, et al., 2008). “Test and treat” is a case in point – a structural intervention to change policy and practice to increase the availability and use of testing and to provide universal treatment for persons found to be infected with HIV. This approach aims to both improve the health and longevity of persons living with HIV (PLWH) and to reduce the potential for continued transmission (Dieffenbach & Fauci, 2009).

As many analysts have pointed out, test and treat will work only if entry into care is timely and sustained and adherence to antiretroviral therapy (ART) is high. Evidence suggests, however, that this is not accomplished for many PLWH, as there is substantial fall off at each stage of the care continuum or “treatment cascade,” from diagnosis to initial linkage to care, retention in care, access to ART, and, ultimately, to viral suppression. For example, in the U.S., under half of all HIV-infected persons were engaged in HIV medical care in 2012, and only about one-third had achieved viral suppression, to the detriment of their own health and the promise for reduced transmission (CDC, 2016; see also Gardner, et al. 2011; Holtgrave, 2010).

New York City (NYC) has done better than the national average in testing, engaging, prescribing ARVs, and suppressing HIV load among people with HIV. Nonetheless, late entry into care after diagnosis presents substantial challenges. In 2012, 84% of PLWH were linked to care within 18 months of diagnosis, and only 69% was done in a timely fashion within 3 months of diagnosis (NYC Department of Health and Mental Hygiene (DOHMH), 2015).

Figure 1. Engagement in HIV Care among Newly Diagnosed - 2012



Timely linkage to HIV care and regular medical visits are necessary to monitor clinical status of HIV disease, to derive maximal benefit from ART and other treatments, and to control the epidemic. Surveillance data, however, indicate that almost half of NYC PLWH delay either HIV

testing, entry into medical care, or both. Approximately 20% of NYC HIV diagnoses are in persons with concurrent AIDS diagnosis indicating advanced disease and substantial length of time after infection (delayed testing). Among those who test promptly, almost 1 in 3 delay medical care more than 3 months after their HIV diagnosis (DOHMH, 2014).

This report is the first of two reports examining delayed entry or dropping out of HIV medical care. The purpose of this report is to examine: 1) HIV testing and entry into care experiences among PLWH in NYC and in Tri-County, northern suburban region of Westchester, Putnam, and Rockland Counties; 2) patterns of delayed vs. timely entry into HIV care after diagnosis with a focus on both individual characteristics and situational factors associated with delayed entry into care; 3) the reasons that delayers give for not entering HIV care in a timely manner; and 4) a multivariate analysis of risk factors for delayed entry into care. A companion paper will examine retention in care over time, asking similar questions: Who drops out? What predicts dropping out compared to sustained engagement, and what are the reasons people with HIV give for dropping out of the care continuum?

Key Findings

- Among CHAIN study participants diagnosed with HIV in 1996 or later, over 40% of NYC and Tri-County study participants delayed testing after infection, delayed entry into HIV medical care after diagnosis, or both.
- Health problems/ experiencing symptoms is the reason most often given for testing for HIV. Personal motivation based on awareness of risky behavior or simply to know one's status is mentioned much less often (Table 3).
- Persons diagnosed with HIV who delay entry into care are more likely to be male and younger age at diagnosis (<35 years old). There are few differences by race/ethnicity and timely entry into care. Regarding birthplace, in Tri-County only, PLWH born in Puerto Rico have high rates of delay (Table 9).
- Delayers differ from non-delayers by life situation at the time of diagnosis:
 - Recently experiencing homelessness
 - Actively using drugs
 - Having no source of regular income
 - Having no medical insurance or a regular source of medical care prior to diagnosis (Table 6).
- The most common self-reported reasons for delayed entry into care include:
 - In denial about being infected, didn't want to face it
 - Was in jail or prison
 - Was doing drugs, relapsed
 - Felt fine, no symptoms, wasn't sick (Table 7a & 7b).
- Among Tri-County study participants:
 - Neither age at diagnosis, nor gender is associated with delayed entry into care
 - MSM are less likely than PLWH from other risk exposure groups to delay

- Homeless experience, lack of income and active drug use during the year prior to diagnosis are associated with delayed entry into care, consistent with patterns seen in among NYC study participants (Table 6).
- Test site activity, especially active referral and linkage to care by the testing site, has the strongest association with timely entry into care, controlling for socio-demographics, resources and life challenges at the time of diagnosis, or medical or non-medical testing site (Page 20). When test site active linkage is included in the models, many of the other risk factors associated with delayed care (e.g. homelessness) are no longer strong predictors of delay.

Methodology

Study sample

This paper is based on interviews with a sample of adults diagnosed with HIV in 1996 or later. Study participants were recruited from medical clinics and non-medical service programs in 2002-2004 or 2009-2010 in New York City, or 2001-2002, 2004-2006, or 2008-2012 in Tri-County, and enrolled as participants in the Community Health Advisory & Information Network (CHAIN) Project. Agencies and then individuals within agencies or programs were recruited using randomization procedures to enroll a broadly representative sample of PLWH with some contact with the HIV service system in any of the five boroughs of New York City (NYC) or in Tri-County. The current study is based on the testing and care experiences of 863 HIV positive adults: 426 persons were recruited from NYC and 437 from the Tri-County region.¹

Study Variables

Extensive in-person interviews are conducted with CHAIN participants on a wide range of topics. Information is collected about need for and use of medical and supportive services, and demographic, behavioral and well-being measures relevant to service outcomes.

During their initial interview, participants are asked about their experiences being diagnosed with HIV including details of their lives at the time of their HIV diagnosis and their testing experience. A separate set of questions asks about first entry into HIV care. For both testing and care experiences, open-ended questions allowing study participants to describe reasons and motivations in their own words complement responses based on standardized questions. Throughout this report, “Delayers” are defined as participants who took over 3 months from diagnosis to first entry into HIV care (first *evaluation* for treatment). Entry into care within 3 months of diagnosis has been established as the benchmark for timely initiation of care (Torian et al. 2008, IOM 2012). Delayed testing is most often indicated by CD4 below 200 at diagnostic test, the marker for concurrent HIV and AIDS diagnosis, and an indicator of substantial time between infection and testing. CD4 at diagnosis is not available for the CHAIN study; respondent reports of testing because of sickness or HIV-related symptoms (e.g. thrush) are used as a proxy indicator for delayed HIV testing.

¹ For description of the CHAIN methodology and recruitment of study participants see: http://www.nyhiv.org/data_chain.html

Table 1. Sample Characteristics – CHAIN Study Participants Diagnosed 1996-2012¹

	Total Sample (n=)	NYC (426)	Tri-County (437)
Gender	Male	58%	49%
	Female	40%	50%
	Transgender	2%	<1%
Age at Study Enrollment	≤36 years	15%	22%
	36-50 years	57%	48%
	50+ years	29%	30%
Race/ Ethnicity	Black	57%	58%
	Latino	34%	25%
	White	7%	14%
	Other	3%	3%
Education	Less than HS/ GED	42%	36%
	HS / GED	43%	43%
	Post-secondary	15%	20%
Income	Below federal poverty level	79%	59%
	Income above poverty level	21%	41%
Marital/ Partner Status	Currently Married	9%	17%
	Has partner	31%	29%
	No spouse/partner	60%	54%
Sexual Orientation	Straight, heterosexual	68%	76%
	Lesbian, gay, homosexual	21%	15%
	Bisexual/Other	11%	9%
Risk Exposure	MSM	28%	19%
	IDU	15%	15%
	MSM/IDU	2%	2%
	Heterosexual/Other	55%	64%
Substance use history²	Ever problem substance user	63%	47%
	Recent problem substance use	22%	17%
	Never problem substance use	15%	36%
Mental health functioning³	Low mental health	48%	45%
	Very low mental health	35%	32%
Incarceration experience	Ever jail/ prison	40%	41%
	Never jail/prison	60%	59%
Stage of illness at study enrollment	Asymptomatic	25%	36%
	Symptomatic	15%	15%
	AIDS	60%	48%

¹ Participant characteristics at baseline interview conducted in 2002-2004 or 2009-2010 in New York City or 2001-2002, 2004-2006, or 2008-2012 in Tri-County

² Lifetime use of heroin, cocaine, crack, or problem drinking. Recent use within past 6 months.

³ Based on SF-12v2 mental health summary score. MCS <42.0. low mental health functioning = clinically significant symptoms; MCS <37.0 very low mental health = mean score in psych inpatient populations.

Coding of the Qualitative Data

Three questions producing qualitative data were used in this analysis. As part of a series of questions about testing and diagnosis, we asked: “(When you found out you were HIV-positive) Why did you take the test then?” To better understand the process of entry into HIV care and services, we asked: “After finding out their HIV status, some people go to get services right away while others let some time go by.” with a follow up question for persons whose answers indicated time to first visit for medical care was more than three months after diagnosis, “Why did you delay in getting medical services?” and for study participants whose first visit within three months, “Why did you decide to go when you did rather than earlier or later?”

The answers to these questions were separated from any contextual data and provided to two coders. Each coder worked independently to create categories of answers. The two coders then met to compare their results, discussing cases of disagreement. Most such cases were resolved in discussion. Answers on which the coders could not agree were brought to the attention of a third coder and discussed once more as a group, in order to achieve consensus. A small number of the answers were very difficult to interpret without additional data. In such cases, the coders checked the relevant elements from the participant’s record – other answers to questions about “what was going on in your life when you first became aware you were HIV positive,” demographics, involvement in a substance or housing program, etc.

Sample Description

The study sample in both NYC and Tri-County is predominantly Black and Latino with a similar age distribution (Table 1). There are more men in NYC (58%) and more women in Tri-County (50%). The poverty rate among PLWH in NYC (79%) is higher than in Tri-County (59%). A higher proportion of NYC than Tri-County study participants have a history of problem substance uses (heroin, cocaine, crack, methamphetamine, or problem drinking) although rates of recent use are similar. Almost half of all participants score ‘low’ on a standardized measure of mental health functioning. About one-fifth was age 35 or younger at study enrollment. The study sample is similar to the demographic and risk profile of Ryan White clients (Wiewel & McAllister-Hollod 2013). Compared to general HIV surveillance data, racial and ethnic minorities and persons with IDU risk exposure are over-represented in the CHAIN study sample.

Results

Delayed Testing, Delayed Entry into Care

Among CHAIN study participants, an estimated 46% of PLWH in New York City and 41% in the Tri-County region were ‘delayers’ – they delayed testing after infection, delayed entry into HIV medical care after diagnosis, or both. More than one-third of PLWH in both jurisdictions delayed testing until they were experiencing symptoms, although, as discussed below, a fair proportion were aware that they had engaged in behaviors putting them at risk for HIV infection. In NYC, 17% of PLWH delayed entering HIV medical care after diagnosis for four months or more, a slightly higher proportion than in Tri-County, where 14% delayed entry into care.

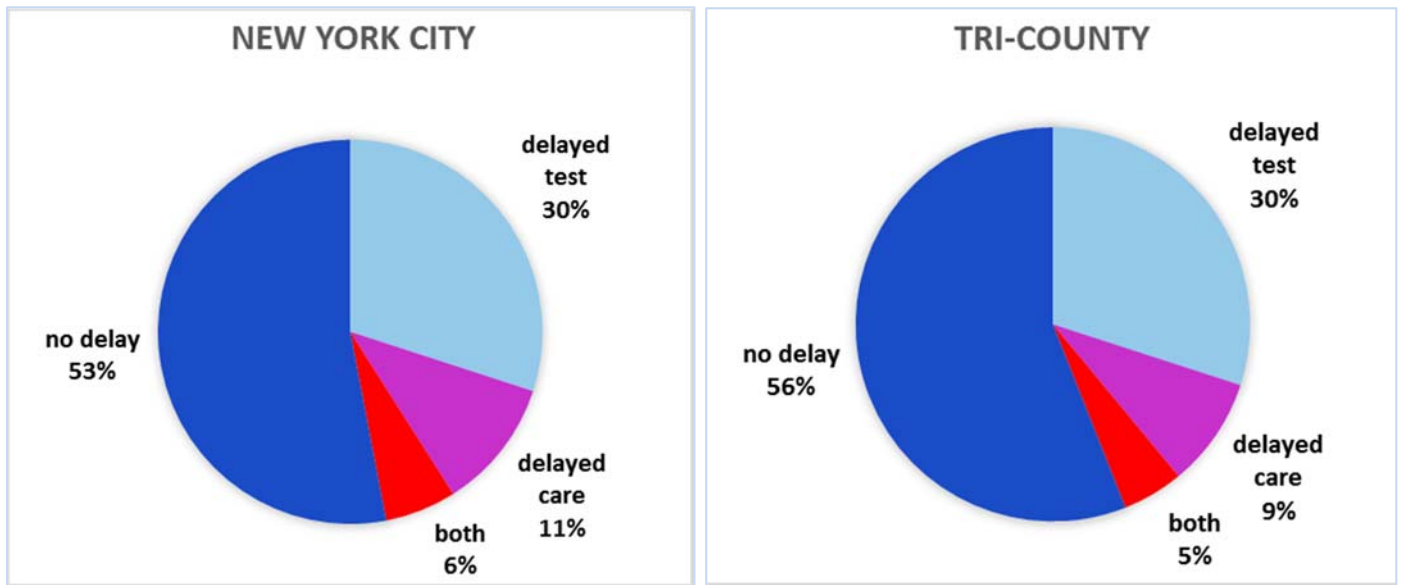


Figure 2. Delayed HIV Testing and Delayed Entry into HIV Care by Area of Residence

Testing, Diagnosis, and Entry into Care Experiences

Table 2 presents more detail about the testing, diagnosis, and entry into care experiences for CHAIN study participants diagnosed with HIV after 1996; 29% in NYC and 44% in Tri-County were diagnosed in 2002 or later. Regardless of year of diagnosis, the mean age at diagnosis was 38-39 years old. Although the proportion of ‘delayers’ was similar for NYC and Tri-County PLWH (17% and 14% respectively), the average length of time after diagnosis to first visit for HIV care was longer among NYC than among Tri-County residents. Among delayers, the time out of care was much longer for NYC residents.

Regarding HIV testing experience, two-thirds of PLWH in both the NYC and Tri-County samples had never even thought about testing prior to when they learned they were HIV positive; a few had thought about it but were never tested previously. Only 21% (NYC) and 26% (Tri-County) had ever had a prior test for HIV and some of these never received the test results. Most people were tested at a medical facility, although one in four in New York City and 15% in Tri-County were tested in a non-medical setting – substance abuse treatment, prison or jail, an AIDS service organization (ASO), or other service setting. The majority of all study participants received risk reduction counseling prior to their diagnostic HIV test and 60% in NYC and 72% in Tri-County received information about treatments available for HIV prior to testing. Current testing protocols recommend that testing sites actively promote linking persons with a positive diagnosis to HIV medical care (NYC DOHMH 2010; CDC 2013; HHS 2015). CHAIN study participants’ descriptions of testing site activities after receiving their diagnosis indicate that many test sites are going beyond just passive referral (e.g. providing a list of medical providers) to arranging appointments, providing escorts or patient navigators, or otherwise taking action to link PLWH to care, although active linkage efforts are far from universal (Table 2).

Table 2. HIV Diagnosis and Entry into Care Experiences

		NYC	Tri-County
Total Sample (n=)		(426)	(437)
Year of HIV diagnosis	1996-2001	71%	56%
	2002-2012	29%	44%
Delayed testing¹	Health problems at diagnosis or HIV symptoms reasons for test	35%	36%
Age at Diagnosis²	Mean (sd):	39.0(9.4)	38.0 (10.7)
	<36 years	36%	40%
	36-50 yrs	54%	49%
	50+ years	11%	11%
Time from diagnosis to HIV care	0-3 months	83%	86%
	4-12 months	9%	9%
	12+ months	9%	5%
	Mean (sd)	4.71(14.0)	3.35 (11.7)
Time to care for delayers	Mean (sd) months out of care if delayed entry into care	24.91(25.6)	19.99 (25.7)
Tested or consider testing before diagnosis	Did not think about it	68%	66%
	Thought about it, didn't get tested	12%	9%
	Got tested, negative	19%	25%
	Got tested, didn't get results	2%	1%
HIV testing site	Hospital clinic	39%	31%
	CHC/HMO/Neighborhood clinic	22%	33%
	Hospital inpatient	8%	9%
	Private practice	7%	12%
	Prison or jail	6%	4%
	Drug treatment/ ASO/ other	18%	11%
Testing site pre-test discussion	Discussed transmission risks	65%	70%
	Discussed treatments for HIV	60%	72%
Testing site linkage to care	Actively facilitated linkage to care after diagnosis	41%	53%
Regular source of medical care prior to HIV diagnosis	Regular source of care	42%	48%
	No Regular Source of care	58%	52%
Health status at first visit for HIV medical care	Had health problems	58%	56%
	No health problems	42%	44%
Provider of first medical care	Hospital clinic	66%	55%
	CHC/Neighborhood Clinic	18%	32%
	Private practice/HMO	6%	7%
	Drug treatment or social service agency	6%	2%
	Prison or jail	4%	3%

¹. Proxy indicator – CD4 count at diagnosis is not available

². Among study participants, age 20 or older

Reasons for Testing for HIV

We asked study participants to describe their reason or reasons for taking the HIV test. We used an open coding approach to discover themes in their answers. Table 3 shows the results of this analysis for NYC study participants and Table 4 for PLWH in Tri-County. Note that multiple responses are possible.

As in earlier CHAIN reports (CHAIN 2005_2), reasons for testing can be classified into self-motivated reasons (“I was engaged in risky behavior,” “Just in case, it’s normal for responsible people and sexually active”), other-motivated reasons – either pressured by others (“A friend asked and took me because I was very skinny,” “my doctor recommended it”), or realization of sex or drug partner serostatus or risky behavior (“I had a friend that had been with the same women that I had been with - he turned out positive and said I should get tested”), institutional or organizational capture (“Because I was pregnant – it was mandatory,” “it was required by my program”) or experiencing HIV symptoms (“I had the thrush,” “I was fatigued, weight loss and the whole nine yards and they tested me”).

Experiencing symptoms consistent with HIV infection was the reason most often mentioned for getting tested for both NYC (36%) and Tri-County respondents (34%). Other top reasons for getting tested included because it was recommended by a health care provider or because a sex or drug partner was diagnosed with HIV. Despite the emphasis on incorporating HIV testing into routine health care and preventive care visits, very few tests (3%) were done on the recommendation of a medical provider as part of a general check-up, rather than recommended because of symptoms or an HIV positive or high risk partner.

Entry into HIV Medical Care

The next section of this report examines factors associated with delayed entry into HIV care considering individual characteristics and test site experiences, as well as what was going on in individuals’ lives at the time they learned of their HIV diagnosis.

In earlier CHAIN studies (CHAIN 2003-5a, 2005-2), we found that year of diagnosis was strongly associated with likelihood of delaying entry into HIV care, especially for those diagnosed prior to 1996 and the widespread availability of ART in the New York region. Date of diagnosis is not strongly associated with delayed entry into care among the current sample of PLWH diagnosed between 1996 and 2012. Time to care for persons who delay has also shortened in more recent years. However, among NYC residents diagnosed with HIV in 1996 or later who do not enter care within three months of diagnosis, the length of time out of care was over 2 years (mean 25 months). The length of time before entering care was somewhat less (20 months) among more recently diagnosed Tri-County delayers.

Table 3. Reasons for HIV Test (NYC)¹

	N	%
Health problems/ HIV symptoms were reason for test	150	36.2%
Recommended by doctor or another health provider ²	66	15.9%
I was engaged in risky behavior	60	14.5%
Someone I had sex with or I took drugs with was HIV-positive	56	13.5%
Just curious, wanted to know, wanted to check	33	8.0%
I was in ER or hospital for something and was tested ³	25	6.0%
I was pregnant, tested me, tested my baby	24	5.8%
Part of drug treatment /housing/ jail program ⁴	16	3.9%
Someone I knew was diagnosed with HIV ⁵	13	3.1%
Recommended by non-medical service provider	12	2.9%
Part of routine medical checkup ⁶	11	3.4%
Required by insurance /employment/ other institutional mandate ⁷	9	2.2%
Pressured by family/friend to get tested	8	1.9%
Monetary incentive to get tested	8	1.9%
Was just tested and given results	7	1.7%
Part of changing my life - wanted to know status	6	1.4%
Suspicious of partner, thought engaging risky behavior, partner getting sick or died (unsure of HIV status)	6	1.4%
Other individual, personal reasons	8	1.9%

N= 414 New York City CHAIN participants diagnosed 1996 or later reporting on their reasons for HIV test. Answers to the question: “(When you found out you were HIV-positive) Why did you take the test then?”

1. Multiple responses possible
2. Not part of routine physical exam
3. Not pregnancy related
4. Required or thought was required or strongly recommended
5. Not sex or drug partner
6. Does not include persons who routinely tested for HIV (n=3).
7. Mandatory for employment, insurance, immigration, military, blood donation, court mandate

Table 4. Reasons for HIV Test (Tri-County)¹

	N	%
Health problems/ HIV symptoms were reason for test	140	33.6%
Recommended by doctor or another health provider ²	56	13.4%
Someone I had sex with or I took drugs with was HIV-positive	50	12.0%
I was in ER or hospital for something and was tested ³	34	8.2%
I was pregnant, tested me, tested my baby	31	7.4%
I was engaged in risky behavior	26	6.2%
Just curious, wanted to know, wanted to check	22	5.3%
Pressured by family/friend to get tested	18	4.3%
Required by insurance /employment/ other institutional mandate ⁴	14	3.4%
Recommended by non-medical service provider	13	3.1%
Part of routine medical checkup ⁵	12	2.9%
Suspicious of partner, thought engaging risky behavior, partner getting sick or died (unsure of HIV status)	12	1.9%
Someone I knew tested HIV-positive ⁶	10	2.4%
Part of drug treatment /housing/ jail program ⁷	8	1.9%
Was just tested and given results	7	1.7%
Saw something on media, health notice	7	1.7%
Relationship concern for partner, wanted to date/marry	5	1.2%
Other individual, personal reason	9	2.2%

N= 417 Tri-County CHAIN participants enrolled 2002-2012 reporting on their reasons for HIV test
 Answers to the question: “(When you found out you were HIV-positive) Why did you take the test then?”

1. Multiple responses possible
2. Not part of routine physical exam
3. Not pregnancy related
4. Mandatory for employment, insurance, immigration, military, blood donation, court mandate
5. Does not include persons who routinely tested specifically for HIV (n=3).
6. Not sex or drug partner
7. Required or thought was required or strongly recommended

We examined HIV testing and diagnosis experiences and entry into care post diagnosis (Table 5). Type of testing site – medical or nonmedical – is not associated with time to care after diagnosis. Individuals who were tested because they were sick or experiencing symptoms at the time of diagnosis were only slightly less likely than others to delay entry into care. Pre-test discussions of risks for HIV and how the virus works in the body, as well as pre-test discussions of treatments available for HIV are not associated with lower rates of delay among CHAIN study participants. Post-testing experiences at the testing site are associated with differences in time to care. For both NYC and Tri-County residents, significantly lower rates of delayed entry into care are seen when testing sites actively facilitated linkage to care after diagnosis – made appointments, escorted persons who tested positive to their first medical care visit, or arranged for persons who tested positive to see a medical provider at the same site immediately after diagnosis.

Table 6 examines a number of personal and situational risk factors for delayed entry into HIV care. Younger age at diagnosis (less than 35 years old) is associated with risk for delay among the NYC subsample. Race/ethnicity are not associated with time to first visit for HIV care after diagnosis, nor was place of birth (U.S. vs. other - data not shown). There are no gender differences in delay entry to care among Tri-County residents; men and persons of transgender experience were more likely to delay among NYC study participants. NYC PLWH in the ‘heterosexual/other’ risk exposure group are less likely to delay compared to MSM and persons with a history of injecting drug use.

Life circumstances at the time of diagnosis appear are important predictors of delayed entry into care. Persons actively using drugs when they learned of their HIV diagnosis were more likely to delay. Not having a regular source of medical care prior to diagnosis increases risk for delayed entry into care as did not having medical insurance. Lack of any regular source of income from wages or entitlement income was associated with delay. PLWH who experienced homelessness during the year they were diagnosed with HIV were more likely than PLWH with stable housing to remain out of care for four or more months.

Why delay?

Answers to open-ended questions about reasons for delayed entry into HIV medical care provided during interviews with CHAIN participants offer insight into individual motivations and rationales for delaying entry into HIV medical care after diagnosis. Answers were recorded verbatim and coded according to themes that emerged from respondent narratives. See Tables 7 and 8.

A common theme in explanations for delayed entry into HIV medical care among both NYC and Tri-County study participants was avoidance or denial – the desire to avoid thinking about and/or accepting ‘being an AIDS person’ and the life changes that diagnosis entails. Twenty percent (20%) of NYC delayers and 26% of Tri-County delayers gave explanations such as “I didn't want to accept it... I did not believe this could happen to me,” or “I was in denial - I just couldn't believe it! I felt good.” Although stigma was mentioned explicitly by relatively few respondents, concerns around stigma and rejection likely contribute to denial. Denial contributes to delayed entry into medical care since accepting medical care is admitting HIV positive status to yourself as well as to others. In the words of one respondent, she avoided going for medical care because she was “Afraid to go to clinic because I thought people would find out my status because I was going to clinic.” A related theme was avoidance and attempting not to care about dealing with their HIV: “I don't know. I just did not feel like dealing with issues at the time.” Another respondent answered: “I waited 3 years ‘cause I was still doing drugs and I didn’t care. I was feeling fine, nothing was wrong with my health.”

Table 5. HIV Testing Experience and Delayed Entry into HIV Medical Care

	New York City		Tri-County	
	Delayer ¹	No Delay	Delayer ¹	No Delay
Total sample	17%	83%	14%	86%
Year of Diagnosis				
1996-2001	18%	82%	15%	85%
2002-2012	15%	85%	12%	88%
Time to Care for Delayers by Year of DX				
Diagnosed prior to 2002	21.00 (19) mean(std) months *		23.69 (31) mean(std) months	
2002 or later	37.58 (38) mean(std) months		13.94 (11) mean(std) months	
Where Tested				
Medical Clinic /doctor's office	17%	83%	14%	86%
Non-Medical site	17%	83%	19%	81%
Delayed Testing				
Tested because sick or reported symptoms at time of diagnosis ²	17%	83%	14%	86%
Tested not because sick	17%	83%	13%	87%
Pre-test Discussion: HIV Risk				
Yes	18%	82%	13%	88% #
No, not sure	15%	85%	23%	77%
Pre-test Discussion: HIV Treatments				
Yes	18%	82%	14%	86%
No, not sure	14%	86%	20%	80%
Post-Test Site Activities³				
Actively linked to HIV care	7%	93% *	12%	88% #
Passive referral only or none	23%	77%	21%	79%

Note: Row percentages shown.

¹ First visit for HIV medical care was more than 3 months after diagnosis.

² Respondent reported that being sick was the reason to get tested or separately reported that s/he was very sick or had 'major health problems,' or described HIV symptoms at the time of diagnosis.

³ Testing site actively facilitated linkage to care after diagnosis – made appointment, escorted to first visit, or seropositive persons saw medical provider at same site immediately after test.

*p< .05 # p< .10

Table 6. Delayed Entry into Care by Demographics and Life Circumstances at Diagnosis

	New York City		Tri-County	
	Delayer	No Delay	Delayer	No Delay
Total sample	17%	83%	14%	86%
Age at HIV Diagnosis				
< 36 yr old	24%	76% *	12%	88 %
36 - 50 yrs	12%	88%	16%	84%
50+ yrs	11%	89%	9%	91%
Gender¹				
Female	12%	88% *	15%	85%
Male	21%	79%	13%	87%
Race/ Ethnicity				
White	24%	76%	12%	88%
Black	15%	85%	13%	87%
Latino	21%	79%	16%	84%
Other	0%	100%	18%	82%
Risk Group				
MSM	20%	80% *	2%	98% *
IDU	22%	78%	23%	77%
MSM + IDU	44%	56%	38%	63%
Heterosexual /Other	13%	87%	15%	85%
Housing Year of Diagnosis²				
Stable	15%	85%	14%	86%
Unstable	17%	83%	14%	86%
Homeless	22%	78%	23%	77%

Any Street Homelessness	38%	62% *	na	na
Personal Resources at diagnosis³				
Less than HS education	16%	84%	15%	85%
HS or above education	18%	82%	13%	87%
No regular source of income	25%	75% *	21%	79%
Had regular source of income	14%	86%	13%	87%
No or limited social support	24%	76%	14%	86%
Had social support	16%	84%	15%	85%
Medical Resources at diagnosis				
No medical insurance ⁴	23%	77% *	16%	84%
Had medical insurance	14%	86%	14%	86%
No regular source med care ⁴	21%	79% *	16%	84%
Had regular source med care	12%	88%	12%	88%
Substance Use at diagnosis³				
Drinking a lot	18%	82%	18%	82%
Using drugs regularly	25%	75% *	20%	80% *

Note: Row percentages shown.

¹ Includes 8 persons of transgender experience in NYC 3 delayers, 5 non-delayers, and 1 in Tri-County, non-delayer.

² Past year homeless (slept on streets, in shelter, SRO) or unstable (doubled up, temporary or transitional housing)

³ Resources and substance use behaviors "during the time you first became aware you were HIV positive"

⁴ Prior to HIV diagnosis

*p≤ .05 # p≤ .10

Denying HIV infection is easier for persons who are not symptomatic: “I didn’t believe that I had HIV. I don’t know, I wasn’t feeling sick or anything.” Not experiencing symptoms was given as a reason for delayed entry into medical care among one in 10 of NYC delayers and 7% Tri-County delayers. As one delayer explained “Because when someone doesn’t feel [sick] or have any pain, they don’t go to the doctor.” However, expressions of ‘feeling fine’ as a reason not to access HIV care were heard much less often than among CHAIN study participants interviewed in earlier time periods. Another change in the post-ART era is the relative absence of expressions of “fatalism,” the belief that diagnosis meant that the person was soon to die and there was nothing to do about it also contributed to avoiding medical care: ...”my husband died and I thought I was going with him so what was the point [of going for medical care].” Both changes are consistent with changes in public awareness and attitudes regarding the availability of effective treatments for HIV and the importance of regular medical care for monitoring and disease management.

Another change in explanations for delayed entry into medical care is the absence of avoidance of medications as a major reason to avoid even an initial visit to an HIV medical care provider. In prior reports, fear of medications and side effects was not uncommon – for example: “I was afraid to take the medications, people were dying from it. I was told the medications were toxic and killing people.” Currently, the relatively few expressions of avoiding medications were more often framed in terms of perceived benefits of a healthy lifestyle and self-management of illness: “I felt that my body was handling things ok.”

Active drug use, and the extent to which “chasing after drugs” takes over all other concerns, was another common reason given for delaying medical care: “Because I was using drugs and I didn't pay attention to anything else, it was the most important thing.” Sometimes the HIV diagnosis was a trigger for relapse: “I started drinking again after 7 years.” Other competing life priorities that contributed to delayed access of medical care included dealing with homelessness, work, immigration, or criminal justice issues. Being in jail or prison at the time of diagnosis was given as a reason for delayed seeking of medical care for 12% of NYC delayers.

Although prescription of ART based on CD4 count was the accepted approach until fairly recently, relatively few respondents gave doctor recommendation as a reason not to initiate HIV medical care soon after diagnosis. However, there are still a few of the most recently diagnosed delayers who explain: “I was told that I do not need it because my numbers were still high.”

Specific reasons given for delay between diagnosis and initial visit for HIV care can be coded as ‘personal’ or ‘organizational/structural.’ If we consider being in jail, lacking medical insurance, and following provider recommendations among organizational or structural reasons, approximately 20%-30% of all reported reasons were organizational or structural and the remainder were personal reasons given for delayed entry into care by NYC and Tri-County CHAIN Study participants.

Table 7a. Self-Reported Reasons for Delayed Entry into HIV Medical Care (NYC)¹

	N	%
In denial about HIV - couldn't/didn't want to believe I was infected	13	20.0%
Didn't care, didn't want to deal with it	12	18.5%
In prison/ jail - no services, didn't want services	8	12.3%
Felt fine, wasn't sick, no symptoms	7	10.8%
Homeless, unstable/ dealing with competing needs ²	6	9.2%
Was depressed/ mental health issues	6	9.2%
Was doing drugs/ relapsed	5	7.7%
Medical provider said not needed	5	7.7%
Stigma/ concerned about disclosure	4	6.2%
Dealing with other health needs	4	6.2%
Lacked knowledge about HIV/ didn't know where to go	3	4.6%
Did not have insurance	2	3.1%
Was afraid/ fear	2	3.1%
Didn't want medications/ afraid of side effects	1	1.5%
Fatalism - believed was going to die anyways	1	1.5%
Other reasons: Structural/organizational ³	4	6.2%
Other reasons: Individual, personal reason ⁴	2	3.1%

Total N =65 NYC PLWH who delayed 4+ months prior to first visit for HIV medical care.

Answers to the question: "After finding out their HIV status, some people go to get services right away while others let some time go by. Why did you delay in getting medical services?"

1. Multiple responses possible
2. Not substance use related
3. No care available; needed change providers; life insurance issue, job related etc
4. Was numb, in shock; wanted trace partner, etc.

Table 7b. Self-Reported Reasons for Delayed Entry into HIV Medical Care (Tri-County) ¹

	N	%
In denial about HIV - couldn't/didn't want to believe I was infected	15	25.9%
Didn't care, didn't want to deal with it	7	12.1%
Was doing drugs/ relapsed	5	8.6%
Stigma/ concerned about disclosure	5	8.6%
Felt fine, wasn't sick, no symptoms	4	6.9%
Did not have insurance	4	6.9%
Was afraid/ fear	4	6.9%
Dealing with other health needs	3	5.2%
Homeless, unstable/ dealing with competing needs ²	2	3.4%
In prison/ jail - no services, didn't want services	2	3.4%
Medical provider said not needed	2	3.4%
Lacked knowledge about HIV/ didn't know where to go	2	3.4%
Didn't want medications/ afraid of side effects	2	3.4%
Fatalism - believed was going to die anyways	2	3.4%
Was depressed/ mental health issues	1	1.7%
Other reasons: Structural/organizational ³	3	5.2%
Other reasons: Individual, personal reason ⁴	2	3.4%

Total N =58 TriCounty PLWH who delayed 4+ months prior to first visit for HIV medical care. Answers to the question: "After finding out their HIV status, some people go to get services right away while others let some time go by. Why did you delay in getting medical services? "

1. Multiple responses possible
2. Not substance use related
3. No care available; needed change providers; life insurance issue, job related etc
4. Was numb, in shock; wanted trace partner, etc.

Table 8a. Self-Reported Reasons for Timely Entry into HIV Medical Care (NYC)¹

	N	%
Taking control of my life/caring for myself	110	42.5%
Fear of death	43	16.6%
Felt sick, experiencing symptoms	40	15.4%
Went immediately/services integrated	39	15.1%
Was in the hospital, care provided	13	5.0%
Wanted medication	13	5.0%
Pressure from others	7	2.7%
Overcame fear/denial	4	1.5%
Concern for others	3	1.2%
Because pregnant	2	0.8%
Other reasons: Individual, personal reason	3	1.2%
Other reasons: Structural, organizational	5	1.9%

Total N=259 NYC PLWH who entered HIV care within 3 months after diagnosis.

1. Multiple responses possible

Table 8b. Self-Reported Reasons for Timely Entry into HIV Medical Care (Tri-County)¹

	N	%
Went immediately/ services integrated	97	49.7%
Taking control of my life/caring for myself	31	15.9%
Felt sick, experienced symptoms	15	7.7%
Was hospitalized, treatment provided	13	6.7%
Followed-up on medical referral	8	4.1%
Fear of death	8	4.1%
Wanted medication	8	4.1%
Because pregnant	6	3.1%
Overcame fear/denial	3	1.5%
Pressure from others	3	1.5%
Concern for others	1	0.5%
Other : Personal, individual reasons	4	2.1%
Other: Structural/Organizational reasons	13	6.7%

Total N=195 Tri-County PLWH who entered HIV care within 3 months after diagnosis.

1. Multiple responses possible

What Reasons Are Given for Timely Entry into Care Among Non-Delayers?

Tables 7b and 8b present thematic coding of reasons given for timely entry into HIV care among those who had a first medical visit within three months of diagnosis. Some of the answers are the flip side of reasons given for delay. Experiencing symptoms is associated with no delay in seeking medical care after diagnosis. Overcoming initial fear or denial facilitates accessing care. Integration of services – organizational linkage of testing and medical care to minimize the gap between diagnosis and entry into care - was described by 15% of NYC and half of all Tri-County CHAIN respondents who entered care in a timely fashion. Other common reasons for avoiding delay were expressions of personal agency and wanting to learn about, take charge of, and manage their HIV disease, and expressions of concern for others.

Risk Factor Analysis of Delayed Entry into HIV Care

We conducted a multivariate analysis to examine factors independently associated with delayed entry into HIV medical care, controlling for a range of individual, situational, and testing experience variables. As Table 9 shows, in NYC, the odds of delayed entry into medical care after a positive HIV test result were higher for men (not statistically significant), people who were under 35 years old when diagnosed and for those experiencing a number of life challenges at the time of diagnosis: active drug use, lack of a regular source of medical care (or all of these). Lack of health insurance, health problems at time of testing, and jail or prison experience during the year of diagnosis is associated with higher odds of delayed care although not statistically significant. Gender and age at diagnosis were not predictors among Tri-County study participants; in Tri-County, the odds of delay were higher for PLWH of Hispanic ethnicity (not statistically significant), especially those born in Puerto Rico, and IDU (not statistically significant) and heterosexual risk exposure group compared to MSM. Persons diagnosed in 2002 or later were slightly less likely (not statistically significant) than those with earlier diagnosis date to delay initial visit for HIV care.

Testing factors are strongly associated with entry into HIV medical care. Test site activity, especially active referral and linkage to care by the testing site, has the strongest association with timely entry into care, controlling for all the other factors in the model. In NYC, for example, the odds of delayed entry into care were about one-fourth as high (AOR 0.23, CI, 0.11-0.52) for participants who reported that staff at the testing site where they were diagnosed provided active referral and linkage services, for example, made a medical appointment and/or accompanied them to the appointment, compared to participants who received no or only passive referral information in the form of written brochures or other materials with basic information about HIV and local treatment resources. When test site active linkage is included in the models, many of the other risk factors associated with delayed care are no longer strong predictors. Findings regarding importance of test site active linkage to care are comparable for Tri-County participants for a subset of cases where this information is available; information regarding testing site and test site linkage activities was not collected consistently in all Tri-County interviews.

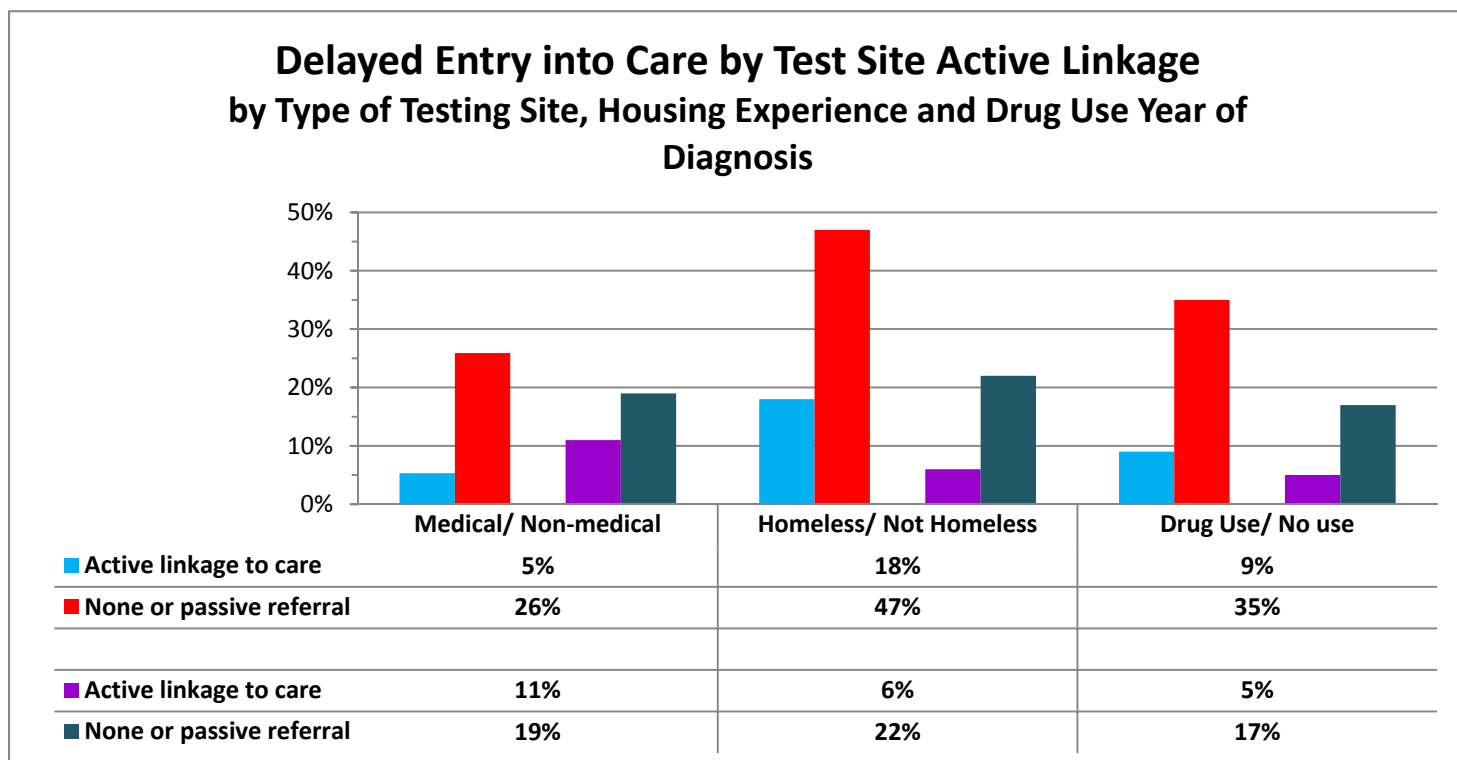
Table 9. Individual, Situational, and Testing Experience Predictors of Delayed Entry into HIV Medical Care

		New York City		Tri-County	
		Un-adjusted OR	Adjusted AOR	Un-adjusted OR	Adjusted AOR
Socio-demographics					
Age at Diagnosis	36-49yrs	1.0			
	≤35years	2.28**	2.58**	0.77	1.17
	50+ years	0.61	1.06	0.59	0.45
Race/Ethnicity	White/Other	1.0			
	Black	0.68	0.87	0.87	0.98
	Hispanic	1.52	1.24	1.26	0.69
Birthplace	US	1.0			
	PR	0.95	0.65	2.73	6.30*
	Other	0.94	0.78	0.81	0.80
Gender	Male	1.0			
	Female	0.54*	0.63	1.15	0.75
Education	HS grad	1.0			
	Less than HS/GED	0.87	0.91	1.11	1.06
Risk Exposure	MSM	1.0			
	IDU/IDU+MSM	1.37	1.61	13.22***	4.46
	Heterosexual/ Other	0.58	0.88	7.11**	6.17*
Life at Time of Diagnosis					
Drinking a lot		1.17	0.74	1.46	1.19
Using drugs regularly		2.38***	2.90**	1.72	1.07
In jail or prison during the past year		1.64	2.34	2.32	3.30
No or limited social support		1.66	1.12	0.90	0.61
Housing during the past year	Stable	1.0			
	Unstable	1.19	0.62	0.96	0.44#
	Homeless	1.63	0.86	1.78	0.97
Did not have health insurance		1.92*	1.76	1.24	1.48
Did not have regular source of medical care		1.94*	2.01#	1.47	1.07
Testing experience					
Year of Diagnosis	Prior to 2002	1.0			
	2002 or later	0.76	0.69	0.77	0.74
Illness or symptoms reason for testing		1.37	1.77	1.22	0.87
Diagnosed at medical site		1.00	2.03	na	
Test site active linkage to care		0.23***	0.24***	na	

Delayed entry into medical care 3+ months after diagnosis. N= 380 NYC CHAIN study participants enrolled in 2002-2004 or 2009-2010; and 296 Tri-County CHAIN study participants enrolled in or 2001-2002, 2004-2006, or 2008-2012 in Tri-County diagnosed with HIV from 1996 to 2012. Note that medical site vs other as place of HIV diagnosis, and test site linkage to care was not asked consistently in Tri-County interviews

p< .10 * p ≤ .05 **p ≤ .01 ***p ≤ .001

Figure 3. Delayed Entry into Care by Test Site Linkage to Care Activity



Discussion

Rates of delayed entry into HIV medical care are currently lower than at earlier phases of the epidemic (Aidala et al. 1999; 2005). However, current campaigns to increase testing must be supported by efforts to develop infrastructure and services to help people with HIV understand the nature and benefits of treatment, and to facilitate their starting HIV medical care soon after a positive HIV test result.

When we examine differences between delayers and non-delayers, we find more differences by life circumstances (e.g. recent homelessness, lack of insurance) at the time of diagnosis than by simple socio-demographic differences (i.e., gender, race/ethnicity). Typical classifications by demographics and risk exposure are probably too crude a measure to distinguish people newly diagnosed with HIV who are most at risk for delayed entry into care. Observed disparities by gender, race, and even age may mask considerations more amenable to intervention including challenging life circumstances at the time of HIV diagnosis - lack of stable housing, recent incarceration, active drug use, and lack of social support. The lack of a regular source of medical care prior to HIV diagnosis increases risk for delayed entry into care and may be a marker for lack of prior experience with accessible and supportive medical care. A history of poor treatment in the past can discourage future treatment seeking.

An important if not crucial point of intervention is the testing site. Test site activity, especially active referral and linkage to care, has the strongest association with timely entry into care in both NYC and in the Tri-County region, controlling for a wide range of socio-demographics, resources and life challenges at the time of diagnosis, and testing factors such as motivation for testing and type of testing site. As shown in Figure 3, among CHAIN study participants most at risk for delaying initiation of HIV care, those who were tested at a site that actively linked them

to medical care were less likely to delay than their counterparts tested at a site without active linkage. For example, among persons who were homeless at the time of their HIV diagnosis, almost half (47%) delayed entry into HIV care compared to 18% delayers among the homeless whose testing site actively facilitated linkages. The differential is even greater among HIV positive individuals actively using drugs at the time of their diagnostic test. An unanticipated finding is that testing at a medical vs non-medical site is not necessarily associated with timely entry into HIV care. Again, test site activity post-diagnosis makes a difference. It may be that expanding HIV testing to a broader array of general medical settings that do not routinely provide or have strong linkages with providers of HIV services holds limited potential to reduce delayed entry into care and to achieve the full benefit of test and treat as a both a treatment and prevention strategy.

A strong recommendation is to expand services available at testing sites beyond providing written referrals to include actively facilitating entry of HIV positive persons into appropriate care, such as direct contact between the test site and medical treatment facility and/or provision of patient escorts. This is precisely the strategy advocated by the HIV Health and Human Services Planning Council of New York in its Early Intervention Services directive approved in 2015. The services directive encourages linkage navigators to facilitate client engagement activities such as scheduling program appointments and coordinating services and documenting successful linkage; coordinating with other service providers who are able to assist the client with treatment; providing referral, accompaniment, and re-engagement with identified medical, behavioral health, and social services; and discussing primary care status measures, primary care provider appointment adherence, and HIV medication adherence with clients (HIV Planning Council, 2015).

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