

# Lost – or just not following up?: Public health effort to re-engage HIV-infected persons lost to follow-up into HIV medical care: 108 (120)

Chi-Chi N. Udeagu, Tashonna R. Webster, Angelica Bocour, Pierre Michel and Colin W. Shepard

**Objective:** Locate persons living with HIV (PLWH) presumed-lost to follow-up (LTFU), and assist them with partner services and linkage to HIV-related care.

**Design:** Locate and facilitate re-engagement in care for PLWH-LTFU in New York City (NYC), with longitudinal follow-up using HIV surveillance registry.

**Settings:** HIV care facilities and communities in NYC.

**Subjects:** PLWH, reported in the NYC HIV surveillance registry who had a NYC care provider and residential address at last report in the registry. Presumed-LTFU was defined as having no CD4 or viral load during the most recent 9 months during the study period July 2008-December 2010.

**Intervention:** Case-workers conducted public health investigation to locate PLWH presumed-LTFU and offered them assistance with partner and linkage-to-care services.

**Main outcome measures:** Results of partner and linkage-to-care services, and reasons for LTFU.

**Results:** From July 2008 to December 2010, 797 PLWH presumed-LTFU were prioritized for investigation; 14% were never located. Of the 689 located, 33% were current-to-care, 5% had moved or were incarcerated, 2% had died, and 59% (409) were verified to be LTFU. Once located, 77% (315/409) accepted clinic appointments, and 57% (232/409) returned to care. Among the 161 who provided reasons for LTFU, the most commonly reported was “felt well” (41%).

**Conclusions:** Health department case-workers helped more than half PLWH-LTFU re-engage in HIV medical care. HIV prevention strategies must include efforts to re-engage PLWH-LTFU in care, for treatment consideration under current treatment guidelines to improve their clinical status and decrease transmission risk.

© 2013 Wolters Kluwer Health | Lippincott Williams & Wilkins

*AIDS* 2013, **27**:000–000

**Keywords:** contact tracing, health departments, HIV, HIV medical care, linkage to care, loss to follow-up, partner services

## Introduction

Current guidelines recommend that persons living with HIV (PLWH) receive regular specialized HIV medical care, including antiretroviral therapy (ART) to achieve a consistently suppressed HIV plasma viral load (VL), because viral suppression is associated with reduced

morbidity, mortality, and probability of sexual transmission to HIV-uninfected partners [1–7]. Despite the widespread availability of ART and relatively generous federal and state government benefits covering ART for PLWH in the United States [8], estimates indicate that only 51% of PLWH receive ongoing HIV-related medical care and 28% PLWH have consistently suppressed VL

Correspondence to Chi-Chi N. Udeagu, MPH, Epidemiology and Field Services Program, Bureau of HIV/AIDS Prevention and Control, NYC Department of Health and Mental Hygiene, 42-09 28<sup>th</sup> Street, 22<sup>nd</sup> Floor, CN-44, Queens, New York 11101.

Tel: +347 396 7636; e-mail: cudeagu@health.nyc.gov

Received: 4 February 2013; revised: 29 April 2013; accepted: 3 May 2013.

DOI:10.1097/QAD.0b013e328362fdde

[9,10]. In New York City (NYC), approximately 45% of PLWH were not receiving regular primary care for HIV infection between 2005 and 2009, and approximately 34% were lost to follow-up (LTFU) after establishing HIV outpatient care [11].

Now, with evidence that ART can significantly reduce sexual transmission of HIV, treatment is increasingly seen as a means for population-wide HIV prevention, a strategy known as “treatment-as-prevention” [4–7,8,11–16]. Perhaps, the central feature of treatment-as-prevention is initiation of ART promptly following HIV diagnosis, which shortens the duration of detectable viremia in an HIV-infected person to the greatest extent possible. However, in order for treatment-as-prevention to fulfill its potential, not only must newly-diagnosed PLWH start ART promptly and adhere without interruption, but those PLWH not engaged in care must return and start or re-initiate therapy as soon as possible [6]. Although efforts to facilitate return-to-care for this latter group have received less attention than those directed to linking all newly-diagnosed to care and promptly suppressing their VL, they hold comparable relevance to the goal of maximizing the length of time that an HIV-infected person is virally-suppressed.

Capitalizing on the long-standing presence of mandatory named HIV and laboratory reporting, we used the NYC HIV surveillance registry to identify HIV-diagnosed persons who, based on their pattern of CD4 and VL, appeared to have entered in care following HIV diagnosis, but were subsequently LTFU. Public health case-workers conducted investigations to locate these PLWH with the goal of offering assistance with partner services and re-engagement in medical care once found. This initiative, launched in 2008, was begun in the context of a wider effort to take a comprehensive public health approach to controlling the HIV epidemic in NYC [17]. In 2006, the health department’s HIV Field Services Unit was created to implement key components of the new approach, beginning with the provision of partner notification and assistance with linkage-to-care to persons newly-diagnosed with HIV (“partner services”) at 8 high-volume HIV clinics in NYC [18,19]. The public health effort described below, to locate and re-engage PLWH presumed-LTFU in HIV-related medical care was an outgrowth of the Field Services Unit’s collaboration with HIV medical providers, and guided by the public health principle of using systematic treatment and case-management to control an infectious disease epidemic.

## Methods

### Identification of PLWH presumed-LTFU

We used the NYC population-based registry of all persons diagnosed with acquired immune deficiency

syndrome (AIDS) in NYC since 1981 and HIV since 2000 to identify PLWH presumed-LTFU. The registry is continuously updated with incoming-matched HIV-related laboratory results, which since 2005 have included all CD4 T cell-counts, VL results, nucleotide sequences from HIV genotypes, and positive Western blot results. Vital status for PLWH in the registry is updated through quarterly matches with local vital records data, and annual matches to the National Death Index and Social Security Death Master File.

Using a CD4 or VL laboratory report in the registry as a proxy for receipt of HIV medical care, a health department analyst queried the registry quarterly to generate a list of PLWH who had initiated care following diagnosis, but had not had any care during the most recent nine-month period. The resultant list of PLWH presumed-LTFU was narrowed by removing all those whose most recent residential address could not be confirmed to be in NYC via matching to data at NYC social service agencies, and whose last CD4 or VL was not ordered by a Field Services program-affiliated clinical site. We did not prioritize investigations systematically based upon the value of the last CD4 T cell-count or VL of the PLWH presumed-LTFU; because the time elapsed since last CD4 or VL measurement ranged from 9 months to several years, its value could not be relied upon as a consistently accurate reflection of disease status.

### Description of outreach efforts

Case-workers obtained additional locating information (telephone number, address) from other databases within the health department, and conducted medical record reviews at the last known NYC medical provider in the registry. If a PLWH presumed-LTFU appeared to be receiving care for HIV, based on medical record review, outreach efforts were not initiated, and the outcome was recorded as “current-to-care.”

The following stepwise approach was used to locate the remaining PLWH presumed-LTFU, with lack of success in establishing contact prompting each successive step until either the PLWH was located or all potential steps had been exhausted: 1) Phone calls; 2) Letter mailed to last known NYC address requesting that the PLWH presumed-LTFU contact the case-worker regarding important information about their health (HIV is not mentioned specifically); 3) Home visit, with the letter described in #2 left at the home in a conspicuous place (e.g., under the door), if no contact was made with the PLWH-LTFU. Throughout the process, public and subscription online databases and search engines (e.g., correctional facility, metro search, Google, Spokeo) were used to obtain more locating information if necessary. PLWH presumed-LTFU who could not be contacted were classified as “unable-to-locate.”

PLWH presumed-LTFU who returned-to-care following the initiation of contact efforts, but before direct contact was made with a case-worker, were classified as “current-to-care;” contact attempts were discontinued. Contact attempts were also discontinued if the PLWH was found during the investigation to have died, moved, or incarcerated outside NYC.

PLWH presumed-LTFU who responded to contact attempts by either telephoning or agreeing to a face-to-face meeting with a case-worker were asked to confirm that they had not seen an HIV medical specialist in the past nine months. PLWH who confirmed that they were LTFU were offered assistance with re-engaging in HIV care. The case-worker provided names of HIV care facilities close to the PLWH’s residence, or that might otherwise appeal to their stated preferences. For PLWH-LTFU agreeing to re-engage in care, the case-worker would arrange the first appointment for an outpatient visit at the selected provider, and offer transportation from home to the provider in an official passenger vehicle, or reimbursement for public transportation expenses after a kept appointment if preferred. PLWH-LTFU who accepted an appointment were classified as “linked-to-care”. PLWH-LTFU who linked-to-care were also classified as “returned-to-care” if they had an HIV care visit confirmed through medical record review, or CD4 / VL test report in the registry with draw date subsequent to date of linkage-to-care.

PLWH-LTFU who were contacted, but refused assistance with linkage-to-care were given appointments and encouraged to keep them, or to contact the case-worker at any future time for assistance with linkage-to-care. These PLWH were classified as “refused linkage-to-care”, which remained fixed regardless of whether the PLWH subsequently returned-to-care without a case-worker’s assistance.

### Partner services

All PLWH-LTFU were offered assistance with partner services according to previously-described procedures [18,19]. Partner Services entail the identification and notification of HIV-exposed sex or needle-sharing partner, and an offer of HIV testing (Orasure Technologies Inc, Bethlehem, PA) following notification. Partners testing HIV-positive or who were previously positive but LTFU received assistance with linkage-to-care from the case-worker. Standardized codes were used to capture partner service outcomes: unable-to-locate, refused notification, notified but refused testing, and test results. All data gathered during partner services were entered into the program database.

### Evaluation of PLWH LTFU reasons for being out-of-care

We evaluated the reasons that PLWH disengaged from care in NYC by seeking additional interview data from a

subset of PLWH contacted. From July 2008 to December 2009, all located PLWH-LTFU were asked to respond to a short structured case-worker-administered questionnaire regardless of their willingness to re-engage in care. PLWH were informed that the health department was interested in learning about the barriers they experienced in engaging or remaining in care for the purposes of program planning. For each question, PLWH-LTFU were asked to select all appropriate responses from a list of potential responses. Data were entered into “LTFU questionnaire” Microsoft Access database.

### Data analysis

We used three data sources for our analyses: NYC HIV surveillance registry; Partner Services database; and LTFU questionnaire. A unique person-based identifier linked PLWH across these three databases.

We evaluated the effectiveness of our outreach efforts through the following measures: 1) proportion PLWH presumed-LTFU located among all assigned; 2) proportions linked-to-care, returned-to-care, or naming partners for exposure notification among all confirmed-LTFU. For PLWH-LTFU returned-to-care as a result of case-worker’s efforts, we assessed the time between initiation of contact attempts and the first return-to-care visit. We also evaluated retention-in-care among those that were returned-to-care, by measuring the proportion with at least two CD4 or VL reports in the registry, one year following return-to-care visit. We compared these data to the corresponding measures among those PLWH-LTFU who were located, who refused linkage-to-care, but subsequently returned-to-care on their own, within three months of the date they were located.

We summarized socio-demographic characteristics and HIV transmission risk behaviors of PLWH-LTFU whose care status was established; and compared the socio-demographic characteristics of PLWH-LTFU to PLWH found to be current-to-care, and to those who were confirmed-LTFU but refused linkage-to-care. Chi-square statistics were used to compare categorical variables. We used t-tests to compare the mean number of days between initiation of outreach and the return-to-care visits for PLWH who returned-to-care with versus without case-worker’s assistance, and to compare mean CD4 T cell count and VL after returning to care.

Using the LTFU questionnaire data from our evaluation, we examined the most-commonly reported reasons provided by PLWH-LTFU for disengaging from HIV medical care. All analyses were performed using SAS 9.1 software (SAS Institute, Cary, NC) and significance was set at  $P < 0.05$ .

## Results

### Outcomes of PLWH presumed-LTFU

Figure 1 summarizes the outcomes of the 797 PLWH presumed-LTFU assigned for outreach from July 2007 through December 2010. Of these 797, 14% (113) could not be located. Among the remaining 684 who were located, 7% (46) had moved or been incarcerated outside of NYC, or had died.

Of the remaining 638 presumed-LTFU; located and living in NYC, 33% (229) reported, and were confirmed to be current-to-care. Most (73%) of these “current-to-care” were receiving care in NYC, and were misclassified as LTFU due to missing or mis-matched CD4 and VL reports in the registry. The remaining PLWH current-to-care either did not have CD4 or VL reports during care visits in the  $\geq 9$  months prior to being contacted (19%), received care at NYC providers that did not routinely report CD4 or VL to the registry, e.g. Veterans Hospitals (7%), or received HIV care outside NYC (1%).

Among the remaining 409 PLWH located and confirmed-LTFU (Fig. 2), 77% linked to care, and 59% were returned-to-care. Fifty-seven percent had at least one CD4 or VL test performed during the 12-months

following their first return-to-care visit. Forty-eight percent returned to care and had at least two clinic visits during the 12-month period following their initial return to care. Eight PLWH returned-to-care, but did not have CD4 or VL reports in the registry during the 12 months following their initial return-to-care visit. These PLWH may not have followed through with clinicians’ orders for laboratory testing, received laboratory testing that were not reported to the registry, or results were not correctly linked.

### Characteristics of PLWH-LTFU

Fifty-five percent of the 409 confirmed PLWH-LTFU were male, and most were black (67%) or Hispanic (30%), or in the 30–49 years age group (64%) (Table 1). The major risk factors before HIV diagnosis among PLWH-LTFU with identified risks were: history of injection drug use (25%), heterosexual sex (24%) and male:female sex (15%). Approximately one-fifth reported history of incarceration and three-fourths had been LTFU between 9 and 27 months before outreach was initiated. (Table 1) PLWH-LTFU were similar to those 229 PLWH found to be current-to-care with regards to sex, race/ethnicity, country of birth, and transmission risk. PLWH-LTFU were more likely than those current-to-care to be aged 20–49 ( $P = <0.0001$ ).

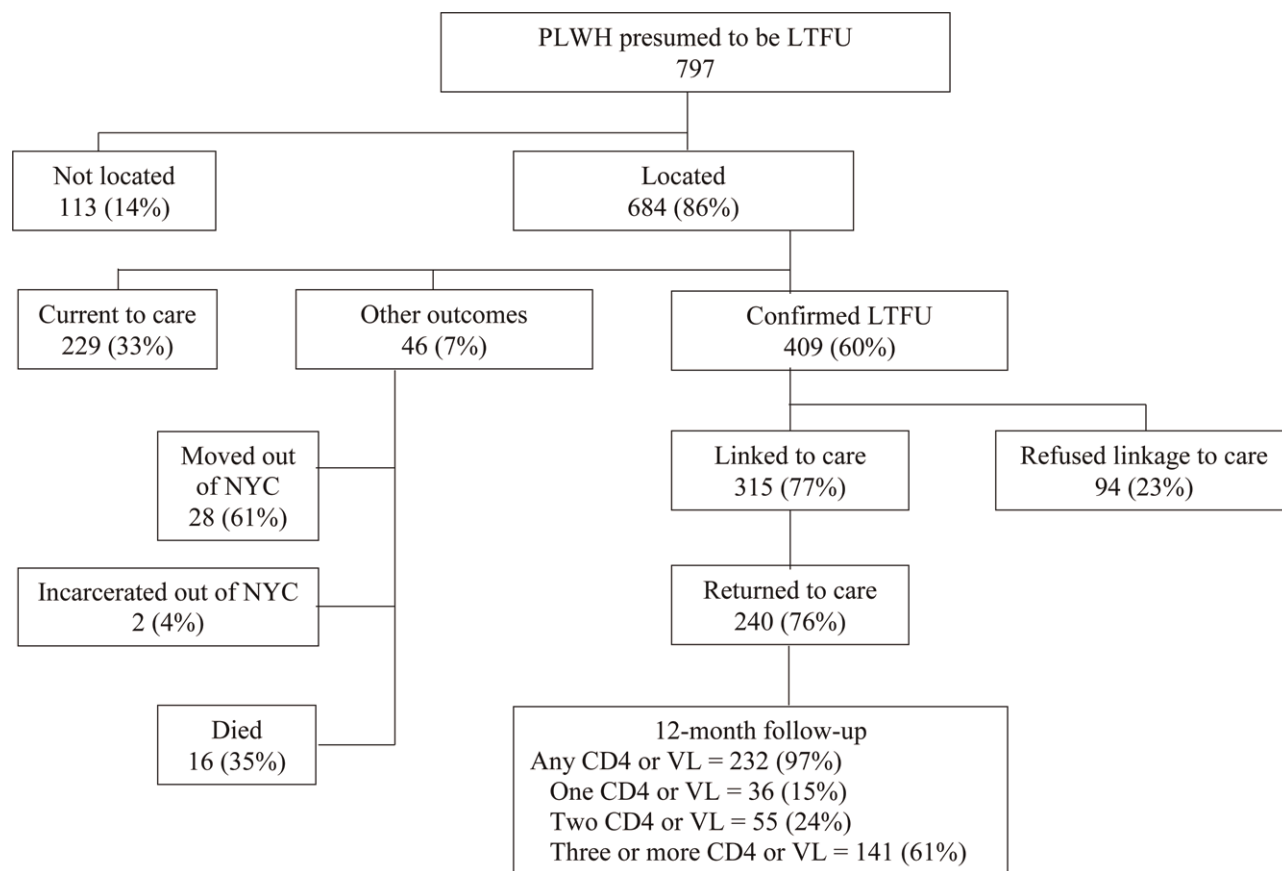
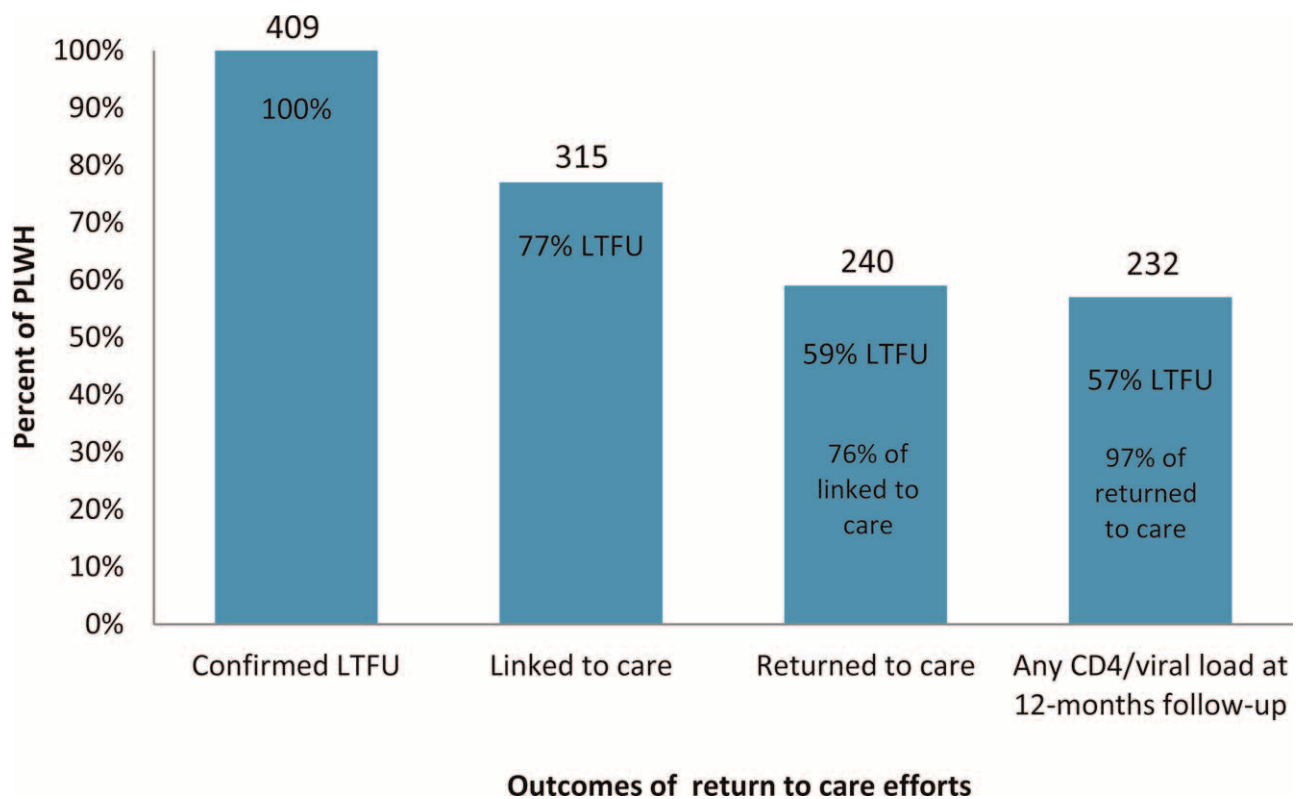


Fig. 1. Flow chart of PLWH presumed lost to follow-up (LTFU) selected from the HIV surveillance registry and assigned for partner services and return-to-care outreach in New York City, July 2008 – December 2010.



**Fig. 2. Outcomes of efforts to return persons living with HIV (PLWH), lost to followup (LTFU) to care in New York City, July 2008 – December 2010.**

### Timeliness of and health status of PLWH-LTFU at the first return-to-care visit

We used the registry to assess outcomes of the 240 PLWH confirmed-LTFU who returned-to-care (Table 2). Most (86%) of this group had their first outpatient HIV care encounter within 3 months of initiation of contact efforts. Ninety-five percent had a VL and 49% had a CD4 T cell count within 12 months of their return. More than half of those with a CD4 T cell count had an initial post-return value <200 cells/mL upon return-to-care, and two-thirds had a CD4 T cell-count less than 350 cells/mL. Most (59%) PLWH-LTFUs' first VL post-return was  $\geq 10,000$  copies/mL and 18% had an initial post-return VL >100,000 copies/mL.

We compared the 240 PLWH-LTFU who returned-to-care to the 169 PLWH-LTFU who, although confirmed-LTFU, either refused linkage-to-care ( $n=94$ ) or were linked but did not return-to-care ( $n=75$ ). These 169 PLWH were similar to the 240 PLWH-LTFU returned-to-care with regards to sex, race/ethnicity, country of birth, and median age. However, this group was much less likely to have had a CD4 or VL reported to the registry in the 12 months following contact by a case-worker (95% vs. 39%,  $p < 0.05$ ).

### Reasons PLWH were LTFU

From July 2008 to December 2009, 161 of the 409 PLWH confirmed-LTFU were interviewed to assess their reasons for lacking recent engagement in care. Of these 161, 63% were returned-to-care (Table 3). Their most commonly reported reason for having been LTFU was that they "felt good" about their health (41%). Sixteen percent reported day-to-day responsibilities and not liking or trusting health care workers. Twelve percent were LTFU because of the effect of HIV medicines, 11% reported feeling depressed, 10% did not have medical insurance, and 9% did not want to think about being HIV-positive. Fewer PLWH (1–6%) reported being LTFU due to difficulty in accessing healthcare providers or social services.

### Partner services

Of the 409 PLWH confirmed-LTFU, 47% (195) agreed to be interviewed for partner services. Twenty-seven percent (52/195) of interviewed PLWH-LTFU named at least one partner; 65 partners were named in all. Of these 65 partners, 57% (37) were notified. Forty-five percent (18/40) of notified partners were already diagnosed with HIV infection when named, and thus were not offered HIV testing. Fifteen of the 22 partners with negative or

**Table 1. Characteristics of HIV-infected patients in New York City confirmed to be lost to follow-up through health department outreach efforts from July 2008 to December 2010 (n = 409).**

Patient characteristic	N (%)
Sex	
Male	226 (55)
Female	183 (45)
Race/ethnicity	
Black, non-Hispanic	274 (67)
Hispanic	123 (30)
White, non-Hispanic	9 (2)
Asian/pacific islander	1 (<1)
Other	2 (<1)
Country of birth	
US	279 (68)
Non-US	60 (15)
Unknown/missing	70 (17)
Age groups (years)	
Median	
13–19	1 (<1)
20–29	48 (12)
30–39	90 (22)
40–49	171 (42)
50–59	75 (18)
>60	24 (6)
Transmission risk before HIV diagnosis	
MSM	62 (15)
Heterosexual <sup>a</sup>	96 (24)
IDU	102 (25)
Perinatal	14 (3)
Other	3 (1)
No identified risk	130 (32)
Other high risk behaviors	
Injection drug use, past 12 months	10 (2)
Non-injection drug use, past 12 months	46 (11)
Alcohol abuse, past 12 months	19 (5)
Sexually transmitted disease, past 12 months	8 (2)
Exchange money for drug or sex, ever	23 (6)
Incarcerated, ever	75 (18)
Time between last medical care and return to care assignment	
≥9 to 18 months	236 (58)
≥18 to 27 months	77 (19)
≥27 to 36 months	38 (9)
>36 months	53 (13)
No laboratory test result	5 (1)

IDU, Injection drug use; MSM, Men who have sex with men; US, United States.

<sup>a</sup>Includes persons who had heterosexual sex with a person they know to be HIV-infected, an injection drug user, or a person who has received blood products. For females only, also includes history of prostitution, multiple sex partners, sexually transmitted disease, crack/cocaine use, sex with a bisexual male, probable heterosexual transmission as noted in medical chart, or sex with a male and negative history of injection drug use.

unknown HIV serostatus tested for HIV; 3 were newly-diagnosed with HIV infection.

## Discussion

“Treatment-as-prevention” efforts have thus far emphasized prompt initiation of ART among the newly-diagnosed [4–8,11–16] as the most important component of this promising strategy. However, this emphasis risks overlooking another equally important group of

PLWH with unsuppressed HIV VL: those who remain un- or under-engaged in HIV medical care.

For several years, mandatory comprehensive HIV laboratory reporting in many jurisdictions has allowed public health officials, using CD4 and VL as proxies for receipt of HIV-related care, to evaluate the size of this population and monitor retention-in-care for the entire population of PLWH. In NYC, we used the HIV registry to measure the HIV-diagnosed population who appeared to be disengaged from HIV medical care, and to identify specific PLWH-LTFU, locate, and provide them with needed assistance for linkage-to-care and partner services.

We learned two valuable lessons: 1) Surveillance data alone has limitations as a tool for identifying PLWH-LTFU, with one-third of our presumed-LTFU found upon further investigation to be current-to-care; and 2) Most PLWH-LTFU were willing to resume HIV care. Only a small proportion refused linkage-to-care, and most PLWH linked-to-care kept their appointments and were evaluated by an HIV care specialist. Most clients who returned-to-care were retained-in-care, as measured by CD4 and VL reports received in the months following return-to-care [20,21]. That only a small proportion of confirmed-LTFU clients not returned-to-care subsequently returned on their own lends additional support to our assertion that case-worker involvement improved re-engagement in care.

Other settings have used more rigorous, research-based methods to examine reasons PLWH are LTFU. Consistent with our findings, these studies have mostly concluded that PLWH disengage from because they feel well and think that HIV medical care may no longer be necessary [22–26]. Like previous studies, we found that the presence of numerous daily responsibilities contributed to poor adherence to care [27–29]. These findings illustrate the challenge and the need to educate PLWH about the effects of untreated HIV infection.

Despite detectable or high VL levels among many of the interviewed PLWH-LTFU, few (13%) named a recent partner for notification compared to persons recently-diagnosed with HIV and interviewed in NYC in 2011, 66% of whom named at least one partner. When judged strictly for its utility in providing partner services to PLWH-LTFU, this program may not be deemed deserving of the scarce resources available for partner services. Nevertheless, in addition to re-engaging PLWH-LTFU in care, we notified exposed partners, including three who were newly diagnosed with HIV as a result of the process.

Consistent with findings from King County, Washington [23], approximately one-third of our PLWH presumed-LTFU based on the registry were actually current-to-care. Although HIV-related laboratory results are transmitted

**Table 2. Characteristics of PLWH confirmed to be lost to follow up and who returned to care following health department outreach efforts, New York City, July 2008 to December 2010.**

	Returned to Care by case workers <sup>a</sup> n = 240 N(%)
Time between initiation of outreach and return to care visit	
Mean days	48
<1 month	93(39)
≥1 to 3 months	112 (47)
≥3 to 6 months	33 (14)
≥6 to 9 months	2 (<1)
First CD4+ cell count after return to care	
Patient with CD4+ cell count	117 (49)
<200	56 (48)
200–349	19 (16)
350–499	20 (17)
≥500	22 (19)
± No CD4+ cell count within 12 months of return	123 (51)
First viral load after return to care	
Patient with viral load RNA	227 (95)
0–399	49 (21)
400–9,999	46 (20)
10,000–99,999	92 (41)
≥100,000	40 (18)
±No viral load RNA within 12 months of return	13 (5)

LTFU, Lost to follow-up; PLWH, Persons living with HIV.

<sup>a</sup>PLWH LTFU who accepted linkage to care by a public health adviser and had evidence of CD4 or VL in HSR.

±No evidence of viral load or CD4+ count test result in the HIV registry during 12-month follow-up.

Note. Individuals may have had CD4 or viral load RNA reported to HSR but not both.

electronically, data processing and matching activities typically result in a lag of at least one month from specimen draw-date before the data can be used by case workers, and 10% of laboratory results have a lag of more than three months. More timely availability of laboratory information would have prevented misclassification of many PLWH as presumed-LTFU, and obviated the use of program resources to establish that they were actually current-to-care. Changes that might result in more timely availability of reports, such as direct reporting from

laboratories to local surveillance systems, should be explored.

Our findings suggest the potential utility of introducing to HIV a system of coordinated case-management between the health department and community providers similar to tuberculosis management. The NYC tuberculosis control model mandates provider reporting of all diagnostic and treatment outcomes directly to the local health department. The health department then uses these data to provide feedback to providers to improve

**Table 3. Reasons HIV-infected patients in New York City in 2008–2009 who had disengaged from regular HIV-related medical care gave for their having been “lost to follow-up”.**

Reasons for loss to follow-up	Number of patients n = 161	%
Personal well being		
Felt good	66	41
Felt depressed	17	11
Was drinking and using illicit drugs	7	5
Felt too sick	4	2
Housing and social services		
Day-to-day responsibilities (child care, work)	25	16
Do not have medical insurance	16	10
Cost of health care	8	5
Do not have stable housing	4	2
Health care and service provider related reasons		
Did not like or trust health care workers	25	16
Inconvenient clinic hours or locations	10	6
Had to wait too long at the clinic	6	4
Could not get an appointment	3	2
Personal beliefs about diagnosis and treatment		
Effects of the HIV medicines	19	12
Do not want to think about being HIV-positive	14	9
There is no cure	3	2
Religious beliefs	2	1
Shared HIV medicines with someone else	1	1

overall case-management services, identify directly for providers who among their patients are not receiving effective treatment or are LTFU, and assist with returning the LTFU to care [17,30]. In NYC, a comprehensive care coordination program has been widely implemented at major HIV outpatient care facilities that supports health system navigation, counseling, assistance with social services, and at some programs, directly observed therapy [31]. These “wrap-around” services show promising signs of improving retention-in-care, but such benefits could be augmented if the health department had broader authority to use HIV registry data to improve case-management [32–35].

Foremost among the limitations of our findings is that we limited the pool of PLWH eligible for outreach to those who linked to a database with recent contact information and who had past engagement with a clinical facility where the Field Services program was already well-established. By doing so we increased the likelihood that PLWH-LTFU could be located, and appointments secured for them if they agreed to return-to-care, however we limited the extent to which our findings are generalizable to the wider population of PLWH reported to the registry and presumed living in NYC, but without laboratory evidence of care. In 2010, this population is estimated to be 39,000 [36]. Had we pursued contact with all presumed-LTFU, our outcomes would be far less favorable because without recent evidence of an NYC residential address, presumed-LTFU are more likely to have relocated and appear (falsely) LTFU.

Many PLWH-LTFU can be found and returned-to-care using outreach techniques familiar to most local health departments. Such a program, however, requires comprehensive and timely HIV laboratory reporting, and that local laws allow the use of HIV registry for partner services and/or case-management. Once these requisite features are in place, optimizing outreach to re-engage PLWH-LTFU relies on moving as close as possible to real time information exchange between public health and clinicians who may encounter PLWH-LTFU. The Louisiana Information Public Health Exchange (LaPHIE), which links that state’s HIV registry with public hospital electronic medical record system to enable electronic alerts when PLWH-LTFU appear for care, is a promising example of such a real-time information exchange [37].

HIV surveillance data can and should be used by health departments to identify and locate PLWH who are LTFU, and public health case-workers should investigate such cases with the goal of re-engaging such PLWH in medical care for HIV. Although challenges abound, such efforts are essential to any comprehensive effort to control the HIV epidemic. “Treatment-as-prevention” cannot be achieved unless most PLWH are on treatment, and

currently thousands of PLWH in the US are not fully engaged HIV medical care many years following their HIV diagnoses. While the cost of deploying case-workers to find PLWH and re-engage them in care will be substantial, it must be weighed against the cost of greater HIV-related morbidity and mortality among PLWH with untreated HIV, and the increased potential for HIV transmission to sex partners.

## Acknowledgements

The authors thank Kent Sepkowitz and James Hadler for their critical review of the manuscript. The authors are grateful to the following Field Services Unit case-workers: Franklin Flores, Jean St. Juste, and Julio Ignacio for their dedication and hard work in locating and assisting HIV-diagnosed persons with linkage to care and partner services; and to Christal Taylor for administrative support.

Authors’ contributions: C. Udeagu designed and directed the program, and led the writing of the manuscript. T. Webster led the data analysis and contributed to the revision of the manuscript. A. Bocour contributed to the design of the data collection instruments, data analysis, and revision of the manuscript. P. Michel supervised the outreach effort, contributed to data collection, performed data entry and data cleaning in preparation of the manuscript. C. Shepard contributed to the conception of the manuscript and provided critical input and guidance in the writing of the manuscript.

Human participant protection: No institutional review board approval was necessary because this is a secondary analysis of data collected as part of the New York City Department of Health and Mental Hygiene routine case and partner services program.

Funding for this program was provided by Ryan White HIV Care program Part A, Grant #93.914.

Data was presented at the AIDS 2012 - Washington DC, USA, July 22–27, 2012

## Conflicts of interest

None declared.

## References

1. Crum NF, Riffenburgh RH, Wegner S, Agan BK, Tasker SA, Spooner KM, *et al.* **Comparisons of causes of death and mortality rates among HIV-infected persons: analysis of the pre-, early, and late HAART (highly active antiretroviral therapy) eras.** *J Acquir Immune Defic Syndr* 2006; **41**:194–200.



2. Holtgrave DR. **Causes of the decline in AIDS deaths, United States, 1995–2002: prevention, treatment or both?** *Int J STD AIDS* 2005; **16**:777–781.
3. Hall HI, McDavid K, Ling Q, Skogget A. **Determinants of progression to AIDS or death after HIV diagnosis, United States, 1996 to 2001.** *Ann Epidemiol* 2006; **16**:824–833.
4. Cohen MS, Chen YQ, McCauley M, Gamble T, Hosseinipour MC, Kumarasamy N, et al. **Prevention of HIV-1 infection with early antiretroviral therapy.** *N Engl J Med* 2011; **365**:493–505.
5. Donnell D, Baeten JM, Kiari J, Thomas KK, Steven W, Cohen CR, et al. **Heterosexual HIV-1 transmission after initiation of antiretroviral therapy: a prospective cohort analysis.** *Lancet* 2010; **375**:2092–2098.
6. Kalichman SC, Cherry C, Amaral CM, Swetzes C, Eaton L, Macy R, et al. **Adherence to antiretroviral therapy and HIV transmission risks: implications for test-and-treat approaches to HIV prevention.** *AIDS Patient Care and STDs* 2009; **24**:271–277.
7. Cohen MS, Gay CL. **Treatment to prevent transmission of HIV-1.** *Clin Infect Dis* 2010; **50**:S85–S95.
8. White House Office of National AIDS Policy. *National HIV/AIDS Strategy for the United States.* Washington D.C: White House Office of national AIDS Policy; 2010 Available at <http://www.aids.gov/federal-resources/policies/national-hiv-aids-strategy/nhas.pdf>. Accessed April 24, 2012..
9. Centers for Disease Control and Prevention (CDC). **Vital signs: HIV prevention through care and treatment – United States.** *MMWR* 2011; **60**:1618–1623.
10. Flishman JA, Yehia BR, Moore RD, Korhuit PT, Gebo KA. **Establishment, retention, and loss to follow-up in Outpatient HIV care.** *J Acquir Immune Defic Syndr* 2012; **60**:249–259.
11. Torian LV, Wiewel EW. **Continuity of HIV-related medical care, New York City, 2005–2009: Do patients who initiate care stay in care?** *AIDS Patient Care and STDs* 2011; **25**:79–88.
12. Hammer SM. **Antiretroviral treatment as prevention.** *N Eng J Med* 2011; **6**:561–562.
13. Abdool Karim Q, Abdool Karim SS, Frohlich JA, Grobler AC, Baxter C, Mansoor LE. **Effectiveness and safety of tenofovir gel, an antiretroviral therapy: a prospective cohort analysis.** *Science* 2010; **329**:1168–1174; Epub 2010 Jul 19.
14. Granich RM, Gilks CF, Dye C, De Cook KM, Williams BG. **Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: a mathematical model.** *Lancet* 2009; **373**:48–57.
15. Panel on Antiretroviral Guidelines for Adults and Adolescents (2011) Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents. Department of Health and Human Services. 1-166.U.S. Available at <http://aidsinfo.nih.gov/guidelines>. Accessed on July 5, 2012
16. DOHMH now recommends offering antiretroviral treatment to any person living with HIV, regardless of the person's CD4 cell count. <http://www.nyc.gov/html/doh/downloads/pdf/ah/nyc-hiv-art-letter.pdf>. Accessed on July 5, 2012.
17. Frieden TR, Das-Douglas M, Kellerman SE, Henning KJ. **Applying public health principles to the HIV epidemic.** *N Eng J Med* 2005; **353**:2397–2402.
18. Udeagu CC, Shah D, Shepard CW, Bocour A, Guitierrez R, Begier EM. **HIV Partner Services Outside STD Clinics: Impact of a Health Department Initiative to Expand HIV Partner Services in New York City.** *Public Health Reports* 2012; **27**:107–127.
19. Udeagu CC, Bocour A, Gale I, Begier EM. **Provider and client acceptance of a health department enhanced approach to improve HIV partner notification in New York City.** *Sex Transm Dis* 2010; **37**:266–271.
20. Mugavero MJ, Davila JA, Nevin CR, Giodano TP. **From access to engagement: measuring retention in outpatient HIV clinical care.** *AIDS Patient Care STDS* 2010; **24**:607–613.
21. Health Resources and Services Administration. HAB HIV Performance Measures: Medical Case Management, 2009. Available at: <http://hab.hrsa.gov/deliverhivaidscafe/files/habpmsmedicalcaseplan.pdf>. Accessed May 8, 2012.
22. Arici C, Ripamonti D, Maggiolo F, Rizzi M, Finazzi MG, Pezzotti P, Suter F. **Factors associated with the failure of HIV-positive persons to return for scheduled medical visits.** *HIV Clin Trials* 2002; **3**:52–57.
23. Buskin SE, Barash EA, Bauer AL. HIV infected individuals presumed to not be receiving HIV medical care: a surveillance program evaluation for investigations and referrals in Seattle, WA. Accessed on May 15, 2012 At <http://www.ieph.org/hase/j-current-issue.htm>.
24. Ndiaye B, Ould-Kaci K, Salleron J, Bataille P, Bonnevie F, Cochonat K, et al. **Characteristics of and outcomes in HIV-infected patients who return to care after loss to follow-up.** *AIDS* 2009; **23**:1786–1789.
25. Nacher M, El Guedj M, Vaz T, Nasser V, Randrianjohany A, Alvarez F, Sobesky M, et al. **Risk factors for follow-up interruption of HIV patients in French Guiana.** *Am J Trop Med Hyg* 2006; **74**:915–917.
26. Lanoy E, Mary-Krause M, Tattevin P, Dray-Spira R, Duvivier C, Fischer P, et al. **Predictors identified for losses to follow-up among HIV-seropositive patients.** *J Clin Epidemiol* 2006; **59**:829–835.
27. McCoy SI, Miller WC, McDonaal PD, Hurt CB, Leone PA, Eron JJ, Strauss ER. **Barriers and facilitators to HIV testing and linkage to primary care: narratives of people with advanced HIV in the Southeast.** *AIDS care* 2009; **21**:1313–1320.
28. Palepu A, Milloy M-J, Kerr T, Zhang R, Wood E. **Homelessness and adherence to antiretroviral therapy among a cohort of HIV-infected injection drug users.** *Journal of Urban Health* 2011; **88**:545–555.
29. Protopopescu C, Raffi F, Roux P, Reynes J, Dellamonica P, Spire B, et al. **Factors associated with non-adherence to long-term highly active antiretroviral therapy: a 10 year follow-up analysis with correction for the bias induced by missing data.** *J Antimicrob Chemother* 2009; **64**:599–606.
30. Frieden TR. **Lessons from tuberculosis control for public health.** *Int J Tuberc Lung Dis* 2009; **13**:421–428.
31. New York City Department of Health and Mental Hygiene. HIV Care, Treatment, and Housing Care Coordination. <http://www.nyc.gov/html/doh/html/ah/hiv-care-treatment-and-housing-ccor.shtml>. Accessed on July 5, 2012.
32. Bradford JB. **The promise of outreach for engaging and retaining out-of-care persons in HIV medical care.** *AIDS Patient Care STDS* 2007; **21 (Suppl 1)**:S85–91.
33. Bradford JB, Coleman S, Cunningham W. **HIV system navigation: An emerging model to improve HIV care access.** *AIDS Patient Care STDS* 2007; **21 (Suppl 1)**:S49–58.
34. Behforuz HL, Farmer PE, Mukherjee JS. **From directly observed therapy to accompagnateurs: Enhancing AIDS treatment outcomes in Haiti and in Boston.** *Clin Infect Dis* 2004; **38 (Suppl 5)**:S429–S436.
35. Cabral XXX, et al. **Outreach program contacts: Do they increase the likelihood of engagement and retention in HIV primary care for hard-to-reach patients?** *AIDS Patient Care STDS* 2007; **21 (Suppl 1)**:S59–S67.
36. New York City HIV/AIDS Surveillance Slide Sets. New York: New York City Department of Health and Mental Hygiene, 2011. Updated February 2013. Care and clinical status of persons with HIV/AIDS in NYC in 2010 as based on HIV surveillance data. Accessed on March 27, 2013 at <http://www.nyc.gov/html/doh/html/data/epi-surveillance.shtml>.
37. Herwehe J, Wilbright W, Abrams A, Bergson S, Foxhood J, Smith L, et al. **Implementation of an innovative, integrated electronic medical record (EMR) and public health information exchange for HIV/AIDS.** *J Am Med Inform Assoc* 2012; **19**:448–452; Accessed from [jamia.bmj.com](http://jamia.bmj.com) on May 7, 2012.