Improving Retention in HIV Care Through New York’s Expanded Partner Services Data-to-Care Pilot

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ABSTRACT

Context: Data to Care (DTC) represents a public health strategy using HIV surveillance data to link persons living with diagnosed HIV infection (PLWDHI) to HIV-related medical care.

Objective: To investigate the feasibility of the DTC approach applied to a Partner Services program serving a geographically diffuse area of New York State.

Design: Disease intervention specialists received training to function as Expanded Partner Services (ExPS) advocates. HIV surveillance data identified PLWDHI presumed to be out of care (OOC). ExPS advocates attempted to locate and reengage OOC individuals in HIV-related care. The pilot ran from September 1, 2013, to August 31, 2014.

Setting: Four upstate New York counties, home to one-third of all PLWDHI in upstate New York.

Participants: A total of 1155 PLWDHI presumed to be OOC.

Main Outcome Measures: Linked to HIV medical care—cases verified as attending 1 or more HIV medical appointments subsequent to case assignment; reengaging in HIV care—any HIV laboratory test in the 6 months following case closure; and retention in HIV care—2 or more HIV laboratory tests in the 6 months following case closure.

Results: The majority of assigned cases (85.3%) were located; 23.7% (n = 233) of located cases confirmed as OOC; and 71.2% of OOC cases (n = 166) were successfully relinked into care. Relinkage success did not differ by gender, transmission risk, or major race/ethnicity categories; however, there was a direct relationship between age and successful relinkage (P < .001). Ninety-five percent of relinked cases reengaged in medical care, and 63.3% were retained in care. Individuals relinked by ExPS advocates were more likely to reengage in care (95%) than individuals interviewed but not relinked to care by advocates (53.7%) and individuals ineligible for the ExPS intervention (34.2%).

Conclusion: DTC can be effective when conducted outside large metropolitan areas and/or closed health care systems. It can also be effectively incorporated into existing Partner Services programs; however, the relative priority of DTC work must be established in this context.

KEY WORDS: data to care, high-impact prevention, HIV/AIDS, Partner Services

Data-to-Care Initiatives

The collection of identifying information on persons diagnosed with HIV/AIDS (HIV surveillance) began in the 1980s to characterize the spread of HIV in the United States. Because there was no effective treatment and because HIV-related stigma and discrimination were rampant in the early days of HIV, many states enacted laws that narrowly defined acceptable uses of HIV surveillance data. Thus, in contrast to other sexually transmitted diseases and tuberculosis, HIV surveillance data have historically not been widely used for disease control.1,2 The advent of effective HIV treatment, coupled with significant legal and social gains for persons living with HIV, has
helped transform societal perception of HIV into a manageable chronic condition.\textsuperscript{3}

The use of HIV data to inform programmatic operations is becoming more accepted. The HIV Care Continuum provides a visual representation of the stages of care that persons with HIV progress through, from initial HIV diagnosis to the ultimate goal of viral suppression.\textsuperscript{4} The Care Continuum portrays the proportion of individuals living with HIV who are engaged at each stage.\textsuperscript{4} The federal government now recommends using surveillance data to improve the HIV Care Continuum,\textsuperscript{2} as improving retention in HIV care is a key goal of the National HIV/AIDS Strategy.\textsuperscript{5} Part of the Centers for Disease Control and Prevention’s High-Impact HIV Prevention initiative, Data to Care (DTC), represents a new public health strategy that aims to use HIV surveillance data to identify HIV-diagnosed individuals not in care, link them to care, and support the HIV Care Continuum.\textsuperscript{6}

Most existing literature on DTC has focused on the impact various linkage-to-care definitions have on the Care Continuum,\textsuperscript{7,8} or validating HIV surveillance–based estimates through field investigation, medical records, direct patient access, or other methodologies.\textsuperscript{9-13} Just a handful of studies have addressed the feasibility of using HIV surveillance data to identify, locate, and link out-of-care (OOC) individuals to HIV medical care. Virtually all of these studies have been limited to closed clinic systems or large urban settings, limiting the generalizability of this work.\textsuperscript{2,14-18} One exception was a study by Bertolli et al,\textsuperscript{17} which summarized efforts by health department staff from 3 states and 2 cities to engage recently diagnosed individuals in HIV care. Results indicated substantial inefficiency with using HIV surveillance data to identify and locate individuals who were truly OOC.\textsuperscript{17}

\textbf{Retention in Care in New York State}

In June 2014, New York State (NYS) became the first state to officially commit to ending its AIDS epidemic. In addition to identifying persons with HIV who remain undiagnosed, and facilitating access to Pre-Exposure Prophylaxis for high-risk persons, Governor Cuomo’s 3-point plan highlighted the importance of linking and retaining HIV-positive persons in health care to maximize virus suppression and to prevent further transmission of HIV.\textsuperscript{19}

DTC work is especially important in NYS, where there are more persons living with diagnosed HIV infection (PLWDHI) than anywhere else in the nation.\textsuperscript{20} At the end of 2014, there were an estimated 123,000 PLWDHI in NYS, approximately 24,000 of whom were residing outside New York City (NYC).\textsuperscript{21} Meaningful scaling of DTC requires that it be implementable beyond large urban centers and closed hospital systems; substantial uptake of DTC requires the approach be applied to all presumed OOC persons and not limited to convenient subsamples of easy-to-reach persons and/or those residing in the largest urban settings. A direct way to accomplish this is to infuse DTC work into Partner Services (PS) programming. PS is an established, evidence-based intervention effective at identifying new cases of HIV infection.\textsuperscript{22,23} A recent study suggests that PS could be a particularly effective strategy for reaching young black men who have sex with men (MSM), who are disproportionately affected by new HIV infections and less likely to maintain sustained access to HIV care.\textsuperscript{23} Moreover, the basic infrastructure for accessing HIV surveillance data is already in place with PS programming, and PS staff are already trained to handle confidential HIV data and to perform most aspects of DTC work.

Areas targeted by this project consist of many suburban and rural communities, where social determinants of health may differ from those in metropolitan areas. Stigma, access to care, and a limited number of providers per area could all impact DTC work outside of metropolitan areas. Furthermore, this project works with individuals who were in care with any provider in NYS. Working with individuals outside of a closed health care system presents unique challenges, as locating information may be less available. This study investigates whether DTC work can be effective when applied outside large metropolitan areas and/or closed health care systems, by evaluating a PS-based DTC pilot project implemented in upstate New York.

\textbf{Methods}

\textbf{Pilot counties}

Contracts to support the Expanded Partner Services (ExPS) pilot were established with 4 county health departments in upstate New York: Erie County (including the city of Buffalo); Monroe County (including the city of Rochester); Onondaga County (including the city of Syracuse); and Westchester County.\textsuperscript{1} These

\textsuperscript{*}Virally suppressed individuals are much less likely to transmit HIV to others than individuals with detectable virus in their blood.
4 counties were home to an estimated 8400 PLWDH1, 35% of all PLWDH1 living in upstate New York’s 57 counties. 2014 surveillance data indicate that 82% of PLWDH1 from these counties had evidence of at least some HIV-related medical care within the past year whereas 67% had evidence of continuous care. Seventy percent of PLWDH1 from targeted counties were estimated to be virally suppressed during 2014. Conversely, nearly 3000 PLWDH1 in targeted counties were not accessing regular medical care for their HIV infection and about 2500 were not virally suppressed at the end of 2014. Each county identified 1 experienced disease intervention specialist to participate in the pilot and used contract dollars to hire replacement staff to perform standard PS functions. The pilot was conducted between September 2013 and August 2014.

Regionally based focus groups were held with medical providers, community stakeholders, and consumers in each pilot county prior to implementation to inform protocol development, notify communities about the pilot, and address any concerns.

**Identifying OOC cases**

Utilizing routinely collected HIV surveillance laboratory data, PLWDH1 with no prognostic or diagnostic laboratory results (viral load [VL], CD4, or genotype) in the prior 13 to 24 months were classified as a presumed OOC cases. These individuals were assigned as cases to each pilot county from the NYS Department of Health’s Central Office in Albany, New York. Cases were assigned through a state-administered electronic HIV case management system, used to conduct Partner Services for newly diagnosed HIV cases in NYS.

**ExPS intervention and investigation outcomes**

The ExPS pilot was standardized across all 4 counties; each county delivered the same services and collected the same data. Cases were assigned to specially trained ExPS advocates, with the specific objective of reengaging individuals in HIV medical care. In addition to national standardized PS training, ExPS advocates were trained in motivational interviewing and internally developed ExPS pilot protocols. Protocols addressed maximizing medical provider participation, strategies for locating OOC patients, prioritizing cases for fieldwork, screening for behavioral risk factors, risk-reduction counseling, helping patients self-notify partners, supportive service referrals, and data entry procedures. To find OOC patients, ExPS advocates searched Regional Health Information databases, conducted vital status verification matches, searched jail and prison directories, conducted LexisNexis Accurint for Government searches, utilized online search engines and networking sites, contacted the last known medical provider, sent non-disease-specific letters to the last known patient residence, conducted phone calls to numbers associated with the patient, and conducted field visits to the last known patient residence.

The following outcomes were used to classify completed ExPS investigations:

**Unable to locate:** Cases where the ExPS advocate was unable to locate the index patient after several attempts and after utilizing multiple investigative methodologies.

**Current to care:** Cases verified as participating in clinical drug trials, cases where HIV-specific laboratory work came in subsequent to case assignment, and cases verified as in care by medical providers or directly by the patient (with substantiating verification).

**Out of jurisdiction:** Cases residing in areas outside the 4-county pilot region, including cases residing in other states.

**Deceased:** Cases determined to be deceased after matching to/reviewing vital statistics.

**Other disposition:** Cases located and contacted where the patient was medically unable to respond, determined to be a duplicate surveillance record, or was found/suspected to be HIV-negative.

**Out of care:** Cases were identified, contacted, and confirmed by the last known provider or the patient himself or herself to be out of HIV care. The following linkage outcomes were recorded for OOC cases:

- **Linked to care by ExPS:** The ExPS advocate verified that the patient attended 1 or more medical appointments subsequent to case assignment.
- **Not linked to care by ExPS:** The patient was located and interviewed but refused assistance, or the patient accepted assistance but attendance at least 1 medical appointment subsequent to case assignment could not be verified.

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2For more information about PS in NYS, see: [http://www.health.ny.gov/diseases/communicable/std/partner_services/prevention.htm](http://www.health.ny.gov/diseases/communicable/std/partner_services/prevention.htm).

3This narrow definition of OOC was used because broader definitions (eg, those without an end date) generated too many case assignments for the 4 staff members assigned to this pilot.

4http://www.cdc.gov/std/training/courses.htm.

5County health departments are limited by Public Health Law to conducting PS work within their respective counties.
For individuals who were located, interviewed, and confirmed to be OOC, advocates collected information on why that individual was OOC. Individuals could cite multiple reasons for being OOC.

**HIV surveillance system follow-up after case closure**

No direct contact was made with individuals following case closure. “Reengaging in HIV Care” was defined as any HIV-specific laboratory work (CD4, VL, or resistance test) reported to NYS in the 6 months following case closure. Retention in HIV care was calculated for the subset of those who reengaged in care. “Retention in HIV care” was defined as the presence of 2 or more HIV laboratory tests, separated by at least 1 week, in the 6 months following case closure.

**Comparison groups**

As a post hoc analysis to evaluate whether the ExPS intervention impacted reengagement or retention in medical care, 3 comparison groups were used: (1) individuals located, interviewed, and relinked to care by an ExPS advocate; (2) individuals located, interviewed, but not relinked to care by an ExPS advocate (includes those refusing assistance and those accepting assistance but lost to follow-up); and (3) individuals located and found to be residing outside one of the 4 pilot county jurisdictions, but within NYS (these individuals had minimal or no contact with ExPS advocates).

**Statistical analysis**

Descriptive analyses of all surveillance-triggered OOC case assignments were conducted to describe the presumed OOC ExPS pilot cohort. To be consistent with the literature, race and ethnicity were combined into 1 variable, and age was recategorized into meaningful groupings. Strata within categorical variables were collapsed because of small cell sizes, if appropriate. Differences in relinkage, as well as reengagement and retention, were examined through bivariate analyses; associations with relinkage were assessed using the \( \chi^2 \) test.

**Human participant compliance**

The ExPS pilot was reviewed by the New York State institutional review board and granted a determination of “nonresearch.”

**Results**

**ExPS pilot project cohort**

A total of 1155 individuals met the surveillance-triggered case definition for presumed OOC. Table 1, Supplemental Digital Content (available at: http://links.lww.com/JPHMP/A248), shows that cases were predominately male (70.0%), black, non-Hispanic (40.4%), and 40 years of age or older (68.4%). Both MSM (37.2%) and MSM who also used intravenous drugs (4.5%) accounted for more than 40% of cases. The demographic characteristics of the pilot cases generally resembled the distribution of all PLWDHI in upstate New York, with the exception of race/ethnicity, in which Hispanics were underrepresented.

**Locating cases and confirming OOC status**

Figure 1 summarizes ExPS case outcomes for the 1155 case assignments during the pilot period. ExPS advocates successfully located 985 of 1155 case assignments (85.3%). Among those located, 39.2% were found to be residing outside the pilot county (out of jurisdiction). Approximately 1 in 4 individuals were confirmed to be OOC (23.7%), whereas approximately 1 in 5 individuals (22.5%) were determined to be current to care. An additional 133 persons (13.5%) were confirmed deceased, whereas the remaining cases (1.1%) were closed with another disposition.

**Reasons for being OOC**

Of the 233 individuals confirmed to be OOC, 180 provided reasons for being OOC. The most commonly reported reasons for being OOC were as follows: (1) day-to-day responsibilities (30.6%); (2) insurance issues, including not having insurance, high costs, and lapse in coverage (23.3%); (3) feeling depressed or stigmatized (19.4%); and (4) having a work or school obligation (15.0%). Less frequently cited reasons included disinterest in care, behavioral health issues, family commitment/issues, distrust/dissatisfaction with the provider, provider transition, lack of transportation, lack of stable housing, adverse effects of HIV medication, other pressing health issues, inconvenient appointment times, forgot appointment, language barrier, did not think they were positive, and no child care.

**Relinkage to care**

The Table displays relinkage rates by demographic and risk-related factors. Of the 233 confirmed OOC cases, 71.2% (n = 166) were successfully relinked into care. Relinkage success did not differ significantly either by gender or by transmission risk. There was a direct relationship between age group and relinkage, with the successful relinkage increasing in each age group, from 55.3% among those aged 20 to

21
29 years to 93.8% among those 60 years and older \( (P < .001) \). Although race/ethnicity was significantly associated with relinkage, no significant differences in relinkage success existed between non-Hispanic blacks, non-Hispanic whites, and Hispanics.

**Reengagement and retention in care**

Of the 166 cases confirmed as relinked to care, 95.2% \( (n = 158) \) had laboratory evidence of reengaging into medical care, and of those, 66.5% \( (n = 105) \) had laboratory evidence of retention in care 6 months following case closure. Reengagement and retention in care did not differ significantly by gender, age group, race/ethnicity, or transmission risk (not shown).

**Impact of the ExPS intervention**

Figure 2 compares reengagement and retention in care by the previously defined comparison groups. The percentage of individuals relinked to care by ExPS advocates who reengaged into medical care (95.2%) was significantly higher \( (P < .001) \) than the percentage observed both for individuals interviewed but not relinked to care by ExPS advocates (53.7%) and for individuals determined to be residing outside ExPS pilot jurisdictions (34.2%). These latter 2 percentages also differed significantly from each other \( (P < .05) \). There were no statistically significant differences observed between the 3 groups in the measure of retention in care, although ExPS advocate–linked individuals had the highest rate of retention at 66.5%.

**Discussion**

**Linkage to, and retention in care**

This study investigated whether similar outcomes to those observed in large cities and/or closed hospital systems could be obtained when DTC work is applied to smaller cities and suburban areas. We found that 71% of OOC individuals were successfully relinked to care by ExPS advocates. This rate is higher than most relinkage rates reported in the literature \( (15-18) \) and approaches the rate obtained in the Louisiana Public Health Information Exchange (LaPHIE) alert system. \( (14) \) Importantly, LaPHIE works with individuals already accessing medical care. Possible keys to the high success rate observed in the ExPS pilot include the use of a limited number of experienced PS staff, the development of specific protocols and

![FIGURE 1 New York State ExPS Pilot Project Outcomes](image-url)
field aids, comprehensive training, and biweekly case conferences between ExPS advocates and program staff. A rapid-cycle evaluation approach was also embraced, using real-time data and ExPS advocate input to make changes to the protocols during the pilot. Examples of changes include switching the case assignment algorithm from provider address to patient address to cut down on out-of-jurisdiction cases, aligning the monthly case assignment schedule with the HIV laboratory processing schedule to reduce the number of laboratory reports received after case assignments were made, and adding the Accurint search tool to assist with locating cases. While these changes did not impact relinkage rates, they did serve to increase the number of assigned cases located and found to be OOC.

We found a strong, positive relationship between age group and relinkage to care. This finding has not been reported in the literature and deserves more investigation.8 New York’s HIV epidemic is being driven by new cases among young men. If these persons end up being harder to reengage in care, then the impact of DTC work, even if successful, will be muted by lower efficacy among younger persons.

We found that 2 in 3 individuals linked to care by ExPS advocates were retained in care. Retention in care was conservatively assessed by the presence of 2 or more HIV-specific laboratory results in the 6 months following case closure. Because many clinicians do not order laboratory results every 6 months, this measure represents a minimum estimate of retention.

Consistent with findings by Udeagu et al18 in NYC, persons relinked to care by ExPS advocates were more likely to show evidence of follow-up HIV care. However, more than 50% of individuals interviewed but not relinked to care by ExPS advocates also returned to care. In addition, 34% of those residing outside ExPS pilot jurisdictions reengaged in HIV care. The statistically significant difference between these last 2 groups suggests that the interaction with an ExPS advocate alone may prompt some individuals to reengage in care.

We did not uncover differences in our measure of patient retention in HIV care among the 3 comparison groups. This is not surprising, since the intervention stopped at the point of reengagement in care: ExPS advocates worked to link persons determined to be OOC back to care, but their involvement with these persons stopped after reengagement was verified.

The most commonly reported reasons for being OOC included day-to-day responsibilities, lack of insurance, and depression, with a variety of other structural barriers reported less frequently. These reasons are consistent with those reported elsewhere in the literature.10,18,25 Encouragingly, many of these reasons are addressable through HIV care coordination and case management programming.

Improving the efficiency of DTC work

Consistent with the literature14-18 we found inefficiency in the ExPS pilot: just 233 of 1155 initial case assignments were confirmed to be OOC. ExPS advocates spent considerable time funneling large numbers of initial assignments into relatively few requiring direct intervention. At least 1 jurisdiction has attempted to reduce this aspect of

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**TABLE**

Expanded Partner Services Cohort Determined to Be Truly Out of Care and Successfully Relinked to Care

| Total confirmed out of care | Relinked to Care | Gender | Age, y | Race/ethnicity |
|----------------------------|-----------------|--------|--------|---------------|
| 233                        | 166             | .30    | <.001b | <.005         |
| Total                       | 100.0           |        |        |               |
| n                          | %               |        |        |               |
| n                          | %               |        |        |               |

**Abbreviations:** IDU, intravenous drug user; MSM, men who had sex with men.

aRepresents row percent.
bTest for trend.
cIncludes females presumed heterosexual contact.
inefficiency by performing upfront surveillance investigations of cases prior to field staff assignment. Adopting this approach in NYS will require additional surveillance resources, to facilitate more than 1000 additional investigations annually. This could be worth the investment, however, as surveillance staff are already experienced in this work and should be able to perform it more efficiently than PS staff. PS staff, in turn, will be able to spend proportionally more time on direct interventions with those determined to be truly OOC.

Some jurisdictions have focused on improving the efficiency of DTC work by incorporating VL status into assignment algorithms. Alaska has focused some of its DTC resources to individuals presumed to be OOC, with most recent VLs registering more than 50,000 copies. ExPS pilot data revealed that just 18% of initial case assignments had a last known VL greater than 10,000 copies/mL. This may be due to the fact that ExPS assignments were no more than 2 years OOC. It is possible that extending the OOC definition beyond 2 years would uncover more individuals with high VL values. Importantly, 44% of those relinking to care with suppressed VL prior to case assignment had detectable VL values upon relinkage. This clearly indicates declining health among many relinked individuals, substantiating the value of working cases irrespective of the last known VL value.

Finally, it is important to consider the resources necessary to conduct DTC work. The ExPS pilot was made possible, in part, through additional contracts with county health departments. The more typical model will likely require the integration of DTC work into standard HIV/STD PS programming. This means determining the priority of DTC investigations compared with PS fieldwork involving new HIV, syphilis, gonorrhea, and chlamydial cases. Since most jurisdictions can only investigate a percentage of newly diagnosed cases, the incorporation of DTC work will need to be at the expense of other PS work. In addition to fieldwork, the ExPS pilot required HIV prevention and surveillance staff to work together in entirely new ways, essentially creating new job functions for both entities. As with fieldwork, DTC work requires a reprioritization of current prevention and surveillance activities.

Moving forward

On the basis of the relative success of the ExPS pilot, we expanded this DTC model into a statewide initiative during 2015. This was accomplished through 6 additional contracts with county health departments, including NYC, and by incorporating this work into our existing NYS PS programming. The statewide model includes a case reassignment algorithm, whereby cases determined to be residing outside the initial assignment county/region are reassigned to the person’s current area of residence. The statewide initiative began in April 2015. As of September 2016, more than 4000 new ExPS case assignments had been made since the end of the ExPS pilot period.

Limitations

There are a few important limitations. The first concerns the comparison group of individuals residing

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**FIGURE 2** Rates of Reengagement and Retention in Care, ExPS Pilot

Abbreviation: ExPS, Expanded Partner Services

- Reengagement significantly more likely among persons relinked to care by ExPS advocate than persons not relinked by ExPS advocate ($P < .001$) and in-state persons not eligible for ExPS intervention ($P < .001$); reengagement more likely among persons not relinked by ExPS advocate than in-state persons not eligible for ExPS intervention ($P < .05$).

- Percentage is out of those who were reengaged into care; difference between groups not significant.
Implications for Policy & Practice

- This study addressed the real-world feasibility of using HIV surveillance data to identify, locate, and link OOC individuals to HIV medical care and demonstrated that DTC can be effective when conducted outside large metropolitan areas and closed health care systems.

- It may therefore be possible to expand DTC work to the national level.

- However, because this work is time- and labor-intensive, and because it has heretofore come without new resources, there is a need to reduce the current inefficiencies in DTC work.

- This study also shows that DTC work can effectively be incorporated into the infrastructure of existing PS programs.

- However, if DTC work is to be sustainably integrated as a function of PS, the relative priority of DTC work must be established.

in NYS but outside the pilot county jurisdiction. Although contact with ExPS advocates was minimal, some contact may have occurred during the investigatory process, leading up to their out-of-jurisdiction determination. This information was not systemically recorded. Contact with these individuals might have influenced their decision to seek care. However, this would only serve to underestimate the impact of the ExPS intervention.

Relatively, it is probable that about 25% of the comparison group individuals determined to be residing outside the pilot county jurisdiction would have been found to be current to care in their new jurisdiction (similar to the percentage of ExPS cases within pilot counties). Thus, our finding that 34% of individuals residing outside the pilot county jurisdiction reengaged in care is likely biased upward by not factoring into account that an estimated 25% of this group was never OOC to begin with. Again, this limitation serves to underestimate the impact of our ExPS intervention.

We were not able to present meaningful analyses by county, as there would be no way to disentangle differences specific to counties from differences caused by the efficacy of individual ExPS advocates. Similarly, time to relinkage could not be evaluated for this study, as the administrative date associated with when a case was assigned did not correspond to the date the investigation began. The definition of retention used in this article was based on the availability of surveillance data, which was limited to 6 months following case closure. Utilizing other definitions of retention, such as those used by the National HIV/AIDS Strategy (at least 2 laboratory results 90 days apart within a 1-year period), may impact case retention estimates. Finally, the number of linked cases in 2 of the 3 comparison groups was small, yielding insufficient power to detect meaningful differences between groups.

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