

## Technical Report

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# Linkage-To-Care: A Success Model

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### ABSTRACT

On July 13<sup>th</sup> 2010 the National HIV/AIDS Strategy (NHAS) set forth a goal of increasing national linkage to care rates from 65% to 85%. A local AIDS Services Organization (ASO) that recently transitioned to a Federally Qualified Health Center (FQHC) in New Orleans, LA, USA had a testing cohort of 2,785 with a consistent 2% positivity rate. Prior to hiring a dedicated Patient Navigator in 2012, agency linkage to care rates hovered around 50%. This article charts how the agency increased its linkage to care rate by 40% over the course of three years and will examine inputs, strategies and best practices of a successful linkage-to-care model implemented in New Orleans, LA, USA.

**KEYWORDS:** HIV/AIDS, Linkage to Care.

**ABBREVIATIONS:** NHAS: National HIV/AIDS Strategy; ASO: AIDS Services Organization; FQHC: Federally Qualified Health Center; PLWHA: People living with HIV/AIDS; HHS: Health and Human Services; HRSA: Health Resources and Services Administration; HAB: HIV/AIDS Bureau; LTC: Linkage-to-care; PN: Patient Navigators; ARTAS: Antiretroviral Treatment Access Study; CTR: Counseling, Testing and Referral; LOPH: Louisiana Office of Public Health; ROI: Release of Information; PMC: Primary Medical Care.

### HISTORY OF PATIENT NAVIGATION

The concept of patient navigation was first initiated by Harold P. Freeman in 1990 at a public hospital in Harlem, New York following the *American Cancer Society National Hearings on Cancer in the Poor in 1989*.<sup>1,2</sup> Intended to bridge the gap between the point of suspicious cancer findings, diagnosis and entry to care, the patient navigation model was focused on the critical window of opportunity to save lives from cancer by eliminating barriers to timely care.<sup>2</sup> Since then, this model has received national recognition, and has been adapted for various chronic and infectious disease continuums of care.<sup>2</sup>

In July 2010, the White House released the National HIV/AIDS Strategy (NHAS), a comprehensive roadmap for reducing the impact of HIV by 2015.<sup>3</sup> As the nation's first-ever comprehensive, coordinated HIV/AIDS effort, one of the goals set forth was to increase access to care and improve health outcomes for People living with HIV/AIDS (PLWHA).<sup>1</sup> As a result of this initiative, the U.S Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) and Special Project of National Significance funded the Systems Linkages and Access to Care for Populations at High Risk of HIV Infection Initiative (the Systems Linkages initiative) aimed to improve linkages of PLWHA to necessary testing, treatment, and care services.<sup>4</sup>

HHS, HAB and HRSA also administer the Ryan White HIV/AIDS Program, a national program that provides financial support to primary medical care and support services for PLWHA.<sup>5</sup> Under this program, the Ryan White administration created different programs to service the need of various communities and populations affected by HIV/AIDS.<sup>3</sup> Part C of

the Ryan White program was created to provide comprehensive medical care in outpatient settings to PLWHA. Part C includes an Early Intervention Services component, which helps fund Linkage-to-care (LTC) initiatives for agencies providing care to PLWHA.<sup>6</sup>

**THE IMPORTANCE OF PATIENT NAVIGATION**

Patient Navigation is an approach used to improve health care delivery by identifying and eliminating barriers to care that impede equitable, quality care.<sup>1,2</sup> Common barriers that exist for people entering into care are transportation, appointment attendance, and competing priorities. Additionally, poverty, unemployment, intimate partner violence, unstable housing including homelessness, hunger, and other issues can prevent people from accessing health care.<sup>7</sup> To better address these barriers, implementation and models vary by setting disease, but the overall goal is to help eliminate barriers to care, provide a system of support, and ensure a seamless transition into treatment.<sup>8</sup> LTC plays an important role in the HIV continuum of care in that it bridges the gap between diagnosis and engagement in care.<sup>1</sup> In 2010 when the NHAS was released, an action step along the continuum of care was to increase LTC from 65% to 85% within in three months of diagnosis by 2015.<sup>3</sup> In July 2015, the White House challenged Patient Navigators (PN) to achieve an 85% LTC rate within 30 days of diagnosis.<sup>6</sup> After the release of the NHAS 2020 strategy, a local community-based organization sought to meet that challenge, using a model that had proven successful since 2012.

This article will detail a successful patient navigation model currently used in New Orleans, Louisiana, USA.

**STREAMLINING THE PROCESS FROM A TO Z – BUILDING A SUCCESSFUL LINKAGE-TO-CARE MODEL**

**Overview of a Model for Success**

Many HIV LTC models are designed following the Centers for Disease Control’s Antiretroviral Treatment Access Study (ARTAS), which used a two-armed randomized controlled study comparing brief strengths-based case management intervention with standard-of-care referrals.<sup>9</sup> The results of this study established best practices for implementation of LTC programming for HIV clinics. In calendar year 2011 this agency administered 2,785 HIV tests with over 2% positivity rate. While the organization’s linkage-to-care rates hovered around 50% in 2011,

the National LTC standard was 66% and Louisiana reported an overall LTC rate of 56%.<sup>10</sup> In June 2012, a community based AIDS Services Organization (turned Federally Qualified Health Center, 2013) in New Orleans, LA, USA adapted the ARTAS model by streamlining the LTC process through one PN which resulted in an increased LTC rate of 33% within the first few months of model implementation. By December 2012, this LTC program had an average rate of 83%. Building on best practices, during the 2014 calendar year the model resulted in an average quarterly LTC rate of 90% (N=108 clients) within 90 days for HIV-positive individuals tested through the agency’s Counseling, Testing and Referral (CTR) program. For PLWHA that were newly diagnosed, a quarterly average LTC rate of 90% (N=68 clients) was achieved within 90 days of their diagnosis. (Table 1)

**Detailing a Successful Model for Linkage-to-care: From Testing to Linkage**

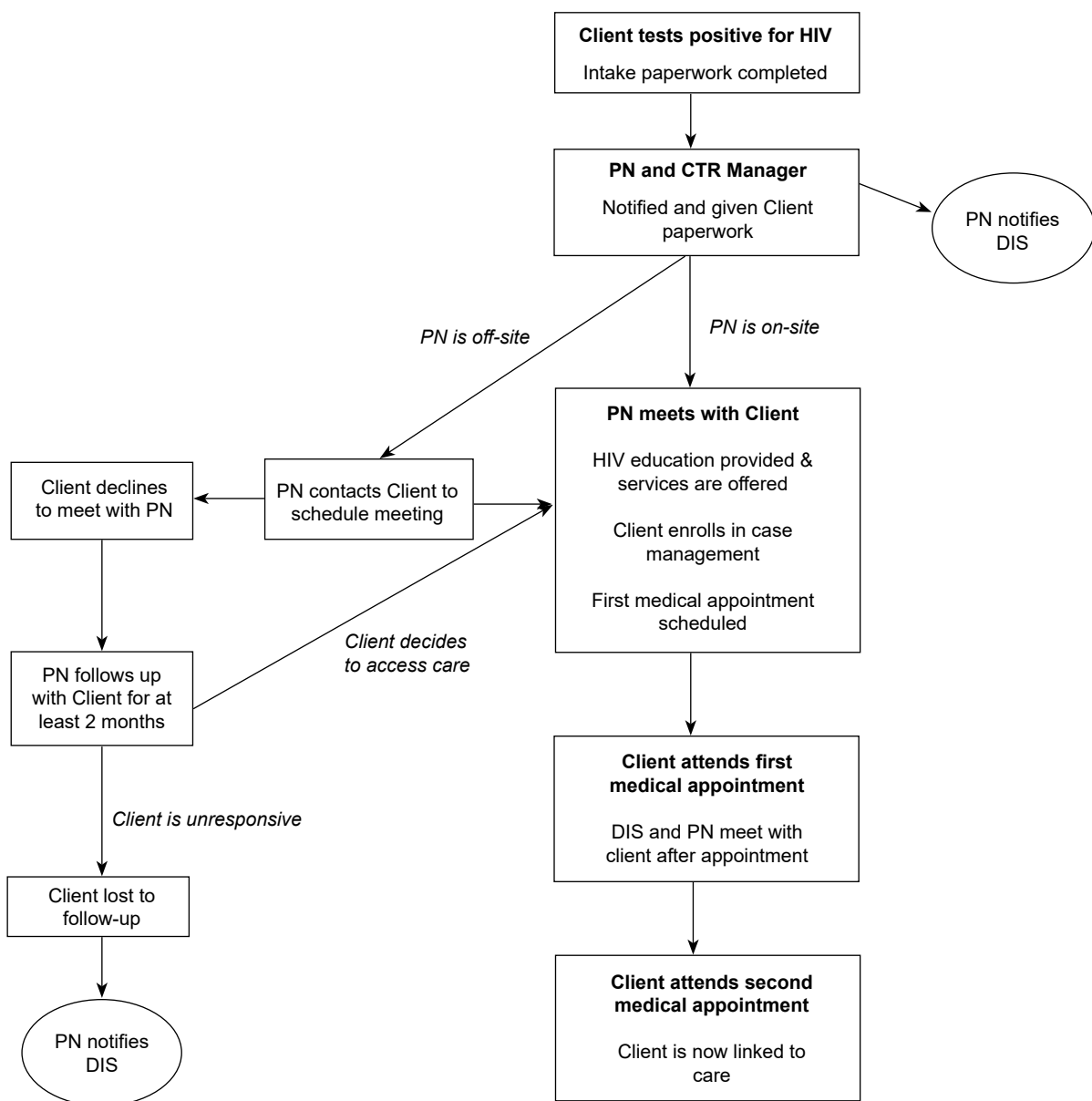
Under this model, the LTC process begins when a client receives two consecutive positive HIV test results on rapid test kits, followed by same-day post-counseling from a state-certified HIV counselor (see Figure 1). When the client is ready to continue, the counselor fills out paperwork mandated both by the Louisiana Office of Public Health (LOPH) and the agency’s CTR program. Included in this paperwork is a Release of Information (ROI) allowing the PN to contact the client. The paperwork also requests the client’s preferred method of contact (email, phone, facebook, etc.), documents the client’s preference on leaving voicemails, and clarifies whether texting is acceptable. In cases where a client is too emotional to proceed through all of the paperwork, the ROI is the only additional information collected and the client is scheduled to come in at a later date to complete the intake paperwork.

Once the CTR session concludes, the counselor immediately notifies the PN and CTR Manager *via* phone, text or email, alerting them of a positive result. If the PN is on-site or nearby, the PN makes contact with and/or meets the client before they depart from the office. If this immediate meeting is not feasible, the client is assured that the PN will reach out to them within 24 hours and given multiple ways to contact the PN themselves. Paperwork is distributed to the PN, who then becomes responsible for ensuring that it is received by the LOPH. Using this model and Continuous Quality Improvement measures, LTC data are effectively tracked by the PN as well as the agency’s electronic health record system and LOPH.

	Test Performed	CTR Confirmed HIV+	Agency LTC Rate
HIV tests performed by case-study agency in calendar year 2011	2785	N/A	~50%
HIV tests performed by case-study agency in calendar year 2012	3131	69	83%
HIV tests performed by case-study agency in calendar year 2013	3407	94	91%
HIV tests performed by case-study agency in calendar year 2014	3864	108	90.5%

<sup>1</sup>Data not available for full year. <sup>2</sup>50% represents Sept.-Dec, 2011 where 8 of 16 newly diagnosed clients testing positive linked to care in less than 90 days.

**Table 1:** Overview of model of diagnosis.



PN: Patient Navigator; CTR: Counseling, Testing & Referrals; DIS: Disease Intervention Specialist with the Office of Public Health

**Detailing a Successful Model for Linkage-to-Care**

The PN calls the client within 24 hours of being notified of a positive result in order to initiate the LTC process. During the call, the PN provides emotional and mental support to the client, and assesses their readiness to link-to-care. If the client indicates that they are ready to move forward, the PN sets up an appointment time for the client to come to the office. Should the client decide that she/he is not ready to engage in care, the PN requests permission to follow-up with the client in the upcoming weeks. If permission is granted, the PN will contact the client at least once a week to maintain rapport until they're ready to move along the continuum of care.

Depending on the client, calls and text messages may

be placed multiple times a day, week or month until the client is linked-to-care.

Once the client decides they are ready to engage in medical care, the PN informs the client of the documentation they will need to bring (proof of Louisiana residency and proof of income) in order to enroll in case management as well as medical services, and schedules a time to meet. If the client does not possess the necessary documents, legal services are provided for them during their first meeting where they can acquire affidavits. During the first in-person meeting with the client, the PN provides an overview of the LTC process and its key components, and discusses any concerns the client may have regarding HIV transmission, health implications, medication adherence, disclosure laws, and other issues as necessary. The PN also provides a

detailed description of medical services offered in the New Orleans metropolitan area, including but not limited to those provided by the host agency, and helps the client identify a clinic or hospital that will meet their needs. This provides the client with more autonomy regarding their medical care.

If the client chooses to receive medical care at the host agency, the PN accesses the clinic's scheduling software and schedules the first medical appointment with the Primary Medical Care (PMC) department. Outside of core PMC staff, the PN is the only other agency staff member allowed to make medical appointments. Immediately after the appointment is scheduled, the client is enrolled into case management services and any additional services that may be needed.

Throughout these linkage steps, the PN provides personalized messages *via* phone, email and/or text message to the client in order to remind them of upcoming medical and social service appointments. This continuous follow-up is meant to provide "red carpet" service and an inviting experience for the client across the continuum of care. At the client's first medical appointment, it is standard to collect an extensive medical history as well as a CD4/viral load in addition to other tests. Once a client has received a blood draw for CD4/viral load within three months of diagnosis, they are considered linked to care by LOPH standards.

In the case that a client does not return initial calls/texts OR ceases to communicate after initial contact, the PN turns the case fully over to the state Disease Intervention Specialists (DIS) and assists them with LTC for the client as needed.

#### **Detailing a Successful Model for Linkage-To-Care: Follow-Up**

After the client attends their first two medical appointments, personalized reminders of appointments from the PN cease, allowing the client to assume greater responsibility for their care. However, the PN monitors appointment attendance and reaches out to the client as needed. The PN may recommend that the client be enrolled in a more intensive tier of case management if they require additional supports. The PN continues to act as a personal advocate and support system for the client, as well as an essential part of their care team.

If a client falls out of care, the PN will reach out to the client to help identify barriers to accessing care. The PN may suggest additional resources to help the client overcome these barriers and ultimately re-engage them in care.

#### **METHODS**

After a client tests positive for HIV, their paperwork is transported to a locked filing cabinet maintained by the PN. The PN transfers client demographic information from their file into an encrypted, password protected excel spreadsheet located on the PN's work computer. As the PN begins to track their progress through the continuum of care, encounters with the client are

documented, along with appointment attendance, initial CD4 and viral load, risk factors and where the client decides to link to care. While preparing data for this paper, the agency was in the process of transitioning to a more secure data management system, Client Track, Inc.®

Information on LTC rates necessary for reporting purposes are pulled from the excel spreadsheet and analyzed manually.

#### **Limitations**

Though data was reviewed at least three times before being incorporated into this paper by two individuals, there is always a small risk of human error.

#### **RESULTS**

The above-mentioned model resulted in an average quarterly LTC rate for newly and previously diagnosed clients. In calendar year 2014, there were 108 confirmed positive HIV tests through this agency's CTR program. Of those, 96 were successfully linked to care within 90 days of diagnosis. Of the 108 confirmed positives, 4 additional clients were linked within greater than 90 days. The 2014 LTC rate of <90 days by quarter was 89%, 100%, 88%, and 85%, respectively, for an average rate of 90.5%. Of the 108 confirmed positives, 68 reported being newly diagnosed; of these, an average quarterly rate of 90% were linked to care (N=60) in less than 90 days. LTC rates for sub-populations such as Men who have sex with men (MSM) and young Black men who have sex with men (YBMSM), data showed MSM (N=52) and YBMSM (N=34) were linked-to-care at a rate of 90% and 88%, respectively.

In July 2015, this agency adjusted reporting protocol to meet updated NHAS goals. For July (N=10) and August (N=4) 2015, 86% of clients were LTC within 30 days of diagnosis. Conversely, independent LTC rates for MSM (N=5) and YBMSM (N=8) LTC <30 days were 60% and 100%, respectively.

#### **DISCUSSION**

##### **The Importance of Collecting and Analyzing Data for Successful Patient Navigation**

Agency employees report that streamlining the LTC process through one person created a simpler approach for HIV counselors, case managers, and providers, and resulted in more complete and accurate data collection. The agency's high LTC rates for 2014 appear to support this conclusion. Prior to hiring a dedicated PN in 2012, multiple employees shared the role of LTC and data tracking. During that time, LTC rates were around 50% and only increased to 83% when LTC was streamlined through one person. In analyzing data, this program found that examining linkage rates for sub-populations is useful in identifying groups that may be underserved or need special attention. For

example, MSM and YBMSM are often referred to in literature as “hard-to-reach populations”.<sup>11</sup> However, this model only saw a 2% difference between the populations.

This agency found it important for partners and funders to have a shared definition and understanding of LTC. For example, it was found that that one grantor considered individuals linked-to-care if a CD4/viral load was drawn within 90 days of diagnosis, while another required clients to have had CD4/viral load drawn *and* have attended at least one appointment with a primary care provider to be considered linked to care. In order to be accountable to different funders and partners, our agency has found that counting, labeling and reporting data according to the requirements of different funding sources while keeping track of linkage numbers beyond the minimum requirements is critical. Finally, it was found that the best LTC is achieved when the PN continues to follow up with clients that did not link-to-care within the 90 period. The data showed that 4 individuals in 2014 were linked to care beyond the 90 day period. Though linkages beyond 90 days may not count towards funding requirements, experience demonstrates the importance of being sensitive to client needs and mindful that clients will move along the continuum of care at their own pace.

#### **The Importance of a Streamlined PN Model, Both for Staff and Clients**

Feedback from clients and agency employees demonstrated that keeping the patient navigation flow simple and concise positively influences clients’ experiences and the efficiency of the PN and reduces clients’ perceived barriers in accessing care. A 2011 study found/recommended increased engagement (patient navigation) at each step in the continuum of care after finding low LTC rates nationally.<sup>12</sup> This agency showed that extended or multiple meetings with a client will often compound barriers to accessing care. Oftentimes, clients become frustrated or lose interest if they are required to return multiple times before receiving medical care. Therefore it is important for providers to realize that many clients may have competing priorities and decreasing the number of visits is likely to augment entry to care. For example, the time it takes to travel to and from multiple enrollment appointments may conflict with clients’ work and familial responsibilities, affect involuntary disclosure, or are prohibitively expensive for the client.

This patient navigation model works to ensure that clients complete the following steps during their first meeting with the PN: completion of all intake paperwork, enrollment in case management services, and scheduling of the first medical appointment. While this results in a lengthy (normally half-day) appointment for the client, feedback from past clients is positive; one long day is preferable to multiple appointments spread out over time. Having the client prepared with all the necessary documents, managing expectations around the time necessary to complete the process, and having snacks on hand are also helpful.

#### **Staff Training and Communication**

This patient navigation program found that training and re-training of HIV counseling staff and volunteers is essential to a achieving a successful LTC model.<sup>13</sup> Testing technologies and protocols change frequently and front line staff must remain up to date in effort to effectively counsel and refer clients to the proper resources. Additionally, allowing the PN to create intuitive intake paperwork influences the success of this model. Experience has shown that convoluted forms and instructions create barriers for both the client and volunteers who provide HIV testing and counseling, and that clear communication from the PN helps staff and volunteers provide clients who have tested positive the most efficient and streamlined transition into care. Furthermore, communication between the PN and the state DIS has proven to be an indispensable tool for this program; in some cases the DIS were able to reach out to clients or share certain data with the PN that assisted in LTC for especially hard-to-reach clients.

#### **Data-Sharing Between Agency Departments & Improved Linkage Outcomes**

Data sharing between prevention staff and primary care staff has been critical to the success of this agency’s patient navigation model, as well as culturally appropriate communication with clients. Information sharing agreements are obtained from the client immediately after they test positive, which enables different actors within the continuum of care to contact the client and offer their services in a timely manner. In addition, beyond the sharing of formal data, there is also the sharing of “soft” data, aka conversations and emails, between prevention and primary care providers. This allows for a more individualized client experience.

A critical component to the success of this patient navigation model is the PN cell phone. The PN maintains a “smart” cell phone purchased by the agency used in all communication with the client. The cell phone is critical to this program’s success for multiple reasons. First off, the cell phone does not show up as a particular agency when it calls a client, which reduces stigma and anxiety for the client. Secondly, this model has demonstrated that clients of all ages prefer communication *via* text message to phone calls and voice mails. Text messages are perceived as less intrusive and intimidating than phone calls and allow the client to respond at their own pace and comfort. Critical to successful client text messaging is the sending of culturally and age appropriate text messages to clients. In particular, “code switching,” or changing the vernacular and delivery of verbal and written communication, is critical to building trust with the client and maintaining their confidence. A randomized control study from March 2015 found that a group of HIV positive clients receiving personalized case-management around linking-to-care were more likely to link-to-care than the control group of HIV positive clients who received standard of care communication.<sup>14</sup> Furthermore, the study found that increased communication (5 interactions) was associated with higher LTC. The cell

phone used at the agency in Louisiana allows for more of this interaction at the client's leisure.

### Addressing Challenges to Successful Linkage-To-Care

Major challenges to LTC for this patient navigation model align with those found nationally. In particular, clients' individual-level and situational variables can present barriers to successful LTC. Financial instability, age, and emotional distress are three of the most challenging barriers to LTC that this agency has found using this model. A lack of finances may result in housing instability or poor access to regular cell phone or internet communication, both of which can impede the ability of the PN to be in regular contact with the client. Age also plays a major factor in the successful linkage of clients to primary care following diagnosis. Staff has found that younger clients are more likely to have unstable living situations and/or be less likely to divulge their status to family members. Youth may have little to no experience navigating the healthcare system as an adult, and are more likely to face challenges understanding the medical implications of their diagnosis and the importance of being proactive about health. Lastly, extreme emotional distress in the form of anxiety, depression, and denial can be an impediment to timely LTC, especially for newly diagnosed clients. This is one reason for the continued long-term follow-up used by this model.

By streamlining the patient navigation model and maintaining close ties with case management and primary care programs at the agency, this model has been successful at addressing the various barriers to LTC faced by clients. Many services are physically housed at the same location as the PN, which enables the client to enroll in and begin receiving services on the same day that they meet with the PN. Early in the program it was noted that clients became frustrated if they had to come back for multiple appointments before seeing a doctor and receiving medication. By limiting the number of initial appointments before seeing a provider, and extending the length of the initial appointment, staff have seen greater LTC when clients enroll in the services the same day as their first appointment with the PN. Furthermore, data sharing agreements allow for fluid communication between programs and with the client. As soon as a client's needs are identified, they can be referred to and access a given program, such as behavioral health, housing or food pantry support. In addition, the agency maintains programs and providers that specialize in working with adolescents and young adults, including a primary care clinic and behavioral health providers that solely serve women and adolescents.

### Health Implications for Patient Navigation

Efficient and patient-centered LTC results in improved physical and mental health outcomes for clients testing HIV-positive, especially those who are experiencing medical complications or mental health issues. Co-housing the PN within the same location as PMC and case management allows for strong professional and social ties between the PN and other agency employees.

The strength of these relationships means that in the event that a client with severe medical complications needs to see a provider more quickly than the normal scheduling would allow, the PN is able to coordinate with providers to expedite their medical care. The trust and respect developed and sustained between the PN and staff within PMC and case management departments is critical to the success of the patient navigation model, and ultimately to the timely and patient-centered care that the model provides to clients.

### Adaptability of this Linkage-to-Care Model for other agencies/organizations

When adapting any service delivery model from one agency to another, undoubtedly there will be a need to deviate from the original model and customize it for different service approaches and protocols. While the overall model presented has a very high LTC rate, different components of the model presented in this article contribute to the agency's rate. Organizations possess varying levels of capacity and each element of this model's approach to LTC will not be necessary or appropriate for every agency. For example, a PN cell phone that doesn't register as a clinic on the caller ID may not be possible if an agency does not have the funds for a dedicated cell phone. In this case, it may prove worthwhile to investigate other forms of communication that allow for that anonymity and a client-centered approach to communication: a dedicated PN Facebook account, a secured PN Gmail/Gchat account for messaging, or a program that allows for FaceTime are all forms of communication that clients may be willing to consent to. For those agencies working to achieve a higher LTC rate, the authors recommended looking at each piece of this model individually to see what may be feasible and useful, instead of trying to implement the full model.

### LIMITATIONS/DISCUSSION

Complete data for 2011 is unavailable due to new program implementation. Data tracking did not become consistent until late 2011. Furthermore, because it was not possible to prepare a control group for the purposes of this paper, it is important to note that other factors could contribute to high LTC rates. During the period in which the PN program was being implemented the agency providing this data was one of the larger and well-known clinics in New Orleans, LA, which may have influenced some of the results. For example, advertisements and targeted outreach during high volume seasons (i.e. Decadence, Mardi Gras, etc.) increases the visibility of the clinic. As a result, individuals that engage in high-risk behaviors during these seasons may have a heightened awareness of the risks and consequences associated with their behaviors. On the other hand, up until 11/11/14 the Louisiana based agency was using a rapid/conventional test (western blot) algorithm for providing a proof of diagnosis. One study from New Jersey found that "many persons who receive preliminary positive rapid test results do not return for their confirmatory test results and thus might not access necessary medical care."<sup>15,16</sup>

This finding from New Jersey did not include a patient navigation model that could help a client navigate the system between tests like the model discussed in this paper. Furthermore, the New Orleans based agency began using a rapid/rapid model for LTC on 11/11/14 and since then has continued to see the same high LTC rates that were achieved prior to the switch. It is recognized that this model's success could have been influenced by the change in testing algorithms.<sup>17-19</sup>

## CONCLUSION

The above technical review provides a detailed description and analysis of the LTC model used at a local health clinic in New Orleans, LA, USA which exceeded the 2015 National HIV/AIDS Strategy (NHAS) goal of reaching an 85% LTC rate, ahead of schedule. This model effectively identifies and decreases traditional barriers to care through the use of innovative algorithms and intradepartmental collaborations. Identifying a PN that is relentless in their approach and culturally sensitive, tech savvy, and self-motivated can help provide equitable access to LTC and medical services. This model is not intended to be used as a one-size-fits-all solution, rather a reference for agencies working to enhance their LTC experience and achieve the updated NHAS goals.

## DISCLOSURE

Ashley King, Caitlin Canfield and Joseph Olsen are all current or former employees of the Federally Qualified Health Center in New Orleans, LA, USA presented in this article.

## CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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