

Implementing a Locator Protocol to Support People Living with Human Immunodeficiency

Virus

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### Abstract

This quality improvement (QI) project implemented and evaluated a locator protocol in an urban hospital to community transitional care program for persons living with HIV to minimize the number of people lost to follow-up.

**Background:** In the United States over 50% of people living with HIV (PLWH) are not engaged in HIV care. Individuals not engaged in HIV care do not have access to combination antiretroviral therapy, prophylactic medications or medical services which increases their risk of morbidity, mortality, and HIV transmission to others.

**Local Problem:** The HIV population in Baltimore is highly transitory with high rates of substance use and mental health disorders, and homelessness. An urban HIV organization in Baltimore, Maryland connects PLWH who are newly diagnosed or out of care to medical care. Clients are enrolled in the transitional care program during hospitalization and staff initiate individualized care plans to address barriers to care and provide support services. After discharge from the hospital clients receive 90 days of intensive case management including home visits, transportation to medical visits and connection to resources. During enrollment in this program, up to 50% of clients may be lost to follow-up at various time points because phone numbers are disconnected, or client transience.

**Intervention:** A locator protocol tool was developed and initiated to collect detailed social and personal information from clients in the transitional care program to minimize the number of clients lost to follow up. Inclusion criteria included consented clients age 18 or older who were newly diagnosed or out of care for HIV for at least six months and had 1 of the following: unstable housing, substance use and/or a mental health disorder. Questions in the locator protocol included local hang outs, identifying a person of trust who could be contacted in case the client was not found, programs, agencies or businesses frequented, and dwelling locations including shelters. Community health workers (CHW) completed the form with clients at the bedside before discharge from the hospital. The locator protocol was initiated if a client missed a medical appointment or when the CHW could not locate a client via phone or address.

**Results:** Twenty clients were enrolled in LTC+ from September 10 to December 17, 2018. Outcomes: 1) Seventeen (85%) clients completed the locator protocol. 2) Clients were frequently lost and then found again with the locator protocol. 3) Thirteen (76%) were actively retained in care.

**Conclusions:** People who have unstable housing, substance use or mental health disorders struggle to maintain their health in traditional medical care models. The locator protocol centralizes client information and standardizes internal protocols which results in more consistent communication between staff and clients. The more detailed social and personal information collected, the longer and more likely staff stayed in touch with clients and got them to appointments and engaged in HIV care.

### **Background and significance**

In the United States over 50% of people living with HIV (PLWH) are not engaged in HIV care (Gardner et al., 2011; Skarbinski, et al., 2015). Baltimore has the fourth highest HIV prevalence rate in the nation and less than half of PLWH are in care (Flynn, 2017). Individuals not in HIV care do not have access to combination antiretroviral therapy (cART), prophylactic medications or medical services which puts them at high risk of morbidity, mortality, and transmitting HIV to others (Metsch et al., 2008). People unaware of their HIV status or who have HIV and are not engaged in care account for 78% of all new infections (Li, Purcell, Sansom, Hayes, & Hall, 2019).

There is a disproportionate burden of HIV among individuals affected by social and economic disparities (Denning & DiNenno, 2017). The prevalence of HIV in the homeless population is as high as 21% versus the general population 0.6% (Beijer & Fazel, 2012). PLWH who experience homelessness have lower adherence to cART, worse health outcomes, higher emergency department and inpatient use and higher rates of HIV risk behaviors (Aidala et al., 2016; Chun, Arora, & Menchine, 2016; Parker & Dykema, 2014). Other groups with poor retention in HIV care include people with poorly managed mental health disorders (Burton et al., 2018) and substance abuse (Dixon, Holoshitz, & Nossel, 2016).

Retention in HIV care is crucial for successful patient outcomes. Primary care HIV guidelines strongly emphasize completing patient visits and medication adherence (Aberg et al., 2013). Clients who miss two HIV appointment within 12 months are two times more likely to die than those who do not miss visits (hazard ratio [HR]= 2.23; 95% CI, 1.79 – 2.80) (Mugavero, et al., 2014). An urban HIV service organization in Maryland connects PLWH to medical care. For a specific subset of patients --those who are newly diagnosed or out of care (OOC) for HIV for at

least six months, most of whom are living with substance use disorders, mental health conditions, or homelessness, the urban HIV organization has developed an evidence-based transitional care model, based on Mary Naylor et al's Transitional Care Model (Hirschman, Shaid, McCauley, Pauly, & Naylor, 2015). This HIV team enrolls eligible PLWH during hospitalizations and implements individualized care plans to address barriers to care. Once discharged from the hospital, the participant receives support which includes continued connection to resources to address barriers, home/community visits, and accompanied medical visits. The goal of the transitional care program is participants will complete two HIV care visits 90 days apart within 6 months, attain viral suppression and not be readmitted within 30 days of hospital discharge. Despite this extensive program, up to 50% of the participants may be lost to follow-up at any given time.

Patients not engaged in HIV care miss timely, appropriate, and specialized medical attention, resulting in costly delayed care with significant physical, mental, and emotional health consequences. Out of care patients are less likely to take cART and become virally suppressed. Per CDC 2016 data, 42.6% of new HIV infections were from PLWH who were not engaged in care (Li, Purcell, Sansom, Hayes, & Hall, 2019). The spread of HIV infection is highly correlated to the concentration of HIV in blood and genital tract secretions. Antiretroviral therapy reduces the viral load and stops the spread of the HIV between sexual partners (Cohen, et al., 2011; Cohen et al., 2016). In 2017, the CDC declared PLWH with an undetectable viral load unable to transmit the virus sexually, hence the importance of maintaining cART and viral suppression for public health (CDC, 2018).

This quality improvement (QI) project implemented and evaluated a locator protocol in an urban HIV transitional care program to minimize the number of people lost to follow-up.

Studies managing people with HIV and tuberculosis that collect detailed social and personal information are more likely to stay in touch with participants and find them after missed appointments (Stergiopoulos et al., 2017; Thomson, Cheti, & Reid, 2011; O'Toole, Johnson, Borgia, & Rose, 2015). The protocol identified information about participant's housing, local hang outs, service organizations frequented, aliases and social supports. In addition, it included local and regional data systems that can be used to locate someone.

### **Goals**

The over-arching goal of the locator protocol was to have detailed descriptive information about the participant that would be helpful in locating them if they were lost to follow-up. The primary long-term goal was to decrease the number of participants lost to follow-up by 25% by the end of the 90-day HIV transitional care program.

The short-term goals for this project were 1) the HIV transitional care team would complete the descriptive information on the locator protocol at participant enrollment with more than 75% of their patients and 2) use the locator protocol 90% of the time when trying to find a patient who is lost to follow-up.

### **Theoretical framework**

The Plan-Do-Study Act (PDSA) model was used as the theoretical framework in this quality improvement project. The PDSA model is endorsed by the Institute for Healthcare Improvement. This model has 4 steps:

- Plan: Plan the project including how to complete data collection to measure results.
- Do: Implement the project on a small scale.
- Study: Analyze the information collected from the project and study the results.
- Act: Refine any changes necessary to the project based on data collected (AHRQ, 2018).

The planning phase of PDSA identified the purpose and reason for the planned activity. This phase determined where the proposed project would take place and who would develop and implement it. In addition, a data collection plan was designed to measure predicted outcomes and results (Institute for Healthcare Improvement, 2018).

The Do phase of PDSA is implementation of the proposed project. Observations and problems were documented, and data collection began. The Study phase analyzed and studied preliminary results. Expected outcomes to actual outcomes were compared. A summary was compiled to reflect on lessons learned. The Act phase of PDSA refined the project for the best results which prepared the team for the next phase of the project (IHI, 2018).

### **Theoretical framework and the connect to care project**

The goal of the locator protocol was to decrease the number of people lost to follow-up after discharge from the hospital to the community. Project planning included:

- Meetings with the HIV transitional care team and precepting with a HIV specialist nurse practitioner in the clinical setting to get a sense of patient needs, clinical management, and flow of the healthcare system from hospitalization to outpatient care.
- Staff interviews to examine current strategies to find participants.
- Identification of locator strategies applied by other healthcare and homeless persons support agencies to reach vulnerable populations.
- Development of the locator protocol based on critical examination of above strategies.
- Work flow modifications to include the locator protocol based on feedback from the transitional care team.

- Development of a monitoring and evaluation process to collect and measure data from the locator protocol for compliance, ease of implementation, and effectiveness of intervention (reduce loss to follow-up).

The Do step of PDSA began fall 2018. Once a PLWH enrolled in the transitional care program during their hospital stay, a team member developed and implemented an individualized care plan for the participant. The care plan included the locator protocol that was completed as part of the assessment. Biweekly meetings with HIV transitional care staff identified problems or unexpected findings from implementation. Data collection and preliminary analysis of the locator tool looked for ease of completion and barriers to implementation.

During the Study step of PDSA, the DNP student analyzed compliance, acceptability, and effectiveness of the locator protocol. Analysis included chart reviews for completion of the locator protocol and staff interviews to assess effectiveness and usefulness. The DNP student analyzed preliminary lost to follow-up data. After analysis of the locator protocol the Act step of PDSA began. The DNP student reviewed results from the locator tool implementation project. Necessary modifications to the protocol and plans for continued use of the protocol were determined.

### **Literature review introduction**

The focus of this literature review is to illustrate the value of implementing a locator protocol to improve HIV retention in care. More specifically, for the purposes of this program, reduce the number of patients lost to follow-up during the transition from hospitalized care to outpatient care. The review begins with the importance of early cART and why it is important to improve retention in care. This is followed by descriptions of successful retention in care programs to engage patients who are lost to follow-up.

## **Analysis of the literature**

### **Early Initiation of cART for Reduced Viral Transmission**

Cohen et al., (2011) enrolled 886 serodiscordant couples in nine countries including the United States into a randomized control study between June 2007 and May 2010. Couples were either randomized to an early or delayed combination antiretroviral therapy (cART) group. To qualify for the study, couples had to be in a stable relationship for at least three months, had vaginal or anal intercourse at least three times and be willing to disclose their HIV status to their partner. In the early cART group, the HIV infected partners start cART immediately. The delayed group started cART after their CD4 count was less than 250 cells per cubic millimeter or after development of an AIDS related illness. There were 28 HIV transmissions between the 886 discordant couples (incident rate, 0.9 per 100 person-years; 95% CI: 0.6, 1.3) of which one was from the early-therapy group (incident rate, 0.1 per 100 person-years; 95% CI 0.0, 0.4). The other 27 HIV transmissions occurred in the delayed-therapy group (incidence rate, 1.7 per 100 person-years; 95% CI, 1.1, 2.5). In conclusion, early initiation of ART in serodiscordant couples reduces the rate of sexual transmission of HIV (Cohen et al., 2011). Limitations to the study included stable HIV discordant couple who may not totally represent all people living with HIV. In addition, they provided ongoing couples counseling and condoms which probably contributed to the low HIV transmission rate (Cohen et al., 2011).

### **Medical Visit Frequency/Adherence**

Analysis of the Antiretroviral Treatment and Access Study (ARTIS) evaluated if being in care reduced HIV transmission rates at one year. This prospective study followed participants for one year from four U.S. cities including Baltimore. Eligibility for the study included not having seen a HIV provider more than once and being treatment naïve. Of the 316 participants, the study

had an 80% follow-up rate at each 6- and 12-month assessment and 97% of the 316 completed at least one of the assessment visits and thus were included in the analysis. PLWH who had at least 3 HIV primary care visits in 6 months were more likely to have abstained from unprotected sex in the last month compared to participants who had completed less than 3 visits (OR, 0.54;  $P=.007$ ) (Metsch et al., 2008). A limitation to the ARTIS analyses is that data were based on self-reports. In addition, participants were recently diagnosed with HIV and possibly more likely to be compliant with medications and reduced risk behaviors compared to those who had been positive for years. Strengths of the study include it was a prospective study and recruited participants from Baltimore (Metsch et al., 2008).

### **Vulnerable/Transient Populations**

The Coordinated Access to Care for Homeless People (CATCH) program in Toronto, Canada aimed to improve access and retention in outpatient care of homeless adults discharged from the hospital. This mixed methods case study design enrolled and consented participants at the bedside. Participants provided program staff access their contact information from government agencies. In addition, they were asked to provide names and phone numbers of family/friends to help minimize attrition. Once discharged from the hospital, participants could access the CATCH clinic which offered primary and psychiatric care and case management. Data was collected from 52 of the study participants in semi-structured focus groups. Findings from the focus groups found that participants appreciated frequent check-ins from case managers either by phone or in-person, quick access to resources and prompt appointments (Lamanna, et al., 2018).

An HIV team in a North Caroline clinic implemented a standardized protocol to locate and re-engage patients in care. Patient navigators and case managers received monthly lists of

patients that had been out of care (OOC) for greater than nine months. Staff called current and past phone numbers and sent letters to encourage patients to contact the clinic. If no response staff investigated local/state and federal prison websites, Social Security Death Index, online obituaries, Medicaid Provider Portal, patients' pharmacies and any known providers such as dentists, dialysis centers and home health agencies. Of the 452 patients who were identified as OOC the patient navigators and case managers were able to reengage 194 patients (43%). In addition, they identified 108 (24%) who were incarcerated, deceased, or had relocated and 150 (33%) who were not found (Keller, et al., 2016). Limitation to the study included the lack of analysis in patients who were retained in care and if that resulted in initiation in cART and lower viral loads. Strengths included the resources dedicated to finding patient who were OOC (Keller, et al., 2016).

Thomson, Cheti, and Reid (2011) implemented a tracing protocol to reduce lost to follow-up rates among HIV, TB and HIV/TB co-infected patients in three Medecins Sans Frontieres clinics in the settlement Kibera in Nairobi, Kenya. This retrospective, descriptive study's tracing protocol included questions embedded in the electronic medical record (EMR) of participants' addresses, phone numbers, places they frequent and their social points of contacts in case they could not be reached. All participants were consented for tracing permission in the event they had missed an appointment. The EMR identified missed clinic appointments and reports were generated for social workers to re-engage participants in care. The social workers completed phone calls, home visits, and reached out to social points of contacts by phone and in person. Data analyzed 1,066 individual attempts to contact participants between April 2008 and March 2009. As a result of implementation of the tracing protocol, the HIV patients lost to care decreased from 21.2% in 2006 to 11.5% in 2009. The strengths of this study include a

standardized protocol to identify and locate patients OOC. Limitations to the study include a lack of statistical analysis besides frequency. It is reasonable to think that some patients would have returned to clinic on their own without the tracing protocol (Thomson et al., 2011).

### **Synthesis of the literature**

Retention in care is a critical factor for improving or maintaining health status and viral load suppression for people living with HIV and key to reducing HIV transmission in populations (Cohen et al., 2011; Dombrowski et al., 2013). Being in care with a HIV primary care provider is associated with reduced risk-taking behaviors and less likely transmission of HIV to others (Metsch et al., 2008). Unfortunately, more than half of all people living with HIV are not engaged in regular HIV care (Gray et al., 2014). To improve health outcomes for PLWH and reduce HIV transmission rates we must provide programs that keep people engaged in medical care. Lamanna et al. (2018) found that program participants stayed engaged in care due to quick and timely connection to resources, frequent phone or in-person “check-ins” from staff and easy access to the clinic. The HIV clinic in North Carolina found that you could engage patients who were OOC with a standardized protocol and dedicated staff (Keller, et al., 2016). The tracing protocol by Thomason, Cheti, and Reid (2011) collected accurate and detailed information about their patients which made it easier to find them. Once patients were located, they were reengaged in care and stayed in care (Thomson, Cheti, and Reid, 2011). Hence, patients who are lost to follow-up can be located with dedicated resources and standardized protocols. Once reengaged in care patients are more likely to start ART, have improved health outcomes and reduce HIV transmission rates to others.

## Implementation

### Description of project

As part of a quality improvement project to increase retention in HIV care a clinical practice locator protocol was completed with participants at enrollment to an urban HIV transitional care program to minimize the number lost to follow up. Lost to follow up was defined by not being in contact with program staff for >10 days after initial enrollment, and a secondary period of not being in contact with the program for >20days after the first two weeks, but before 90 days post enrollment. Inclusion criteria included all participants age 18 or older who were newly diagnosed or out of care (OOC) for HIV management for at least six months who consented to the transitional care program. Participants were enrolled during hospitalization and the locator protocol was completed by community health workers. The estimated sample size (n=24) was based on the average weekly enrollment rate of 2 participants per week over 12 weeks.

### Procedures and Timeline

The QI project was implemented over a 14-week period. The **first two weeks** the project leader trained the 5 HIV transitional care team members in one-hour training sessions. The education session included how to complete the locator protocol form at enrollment and how to use the tool when someone was lost to follow-up. In addition, the training included how data from the protocol tool was collected and recorded for evaluation.

**Weeks two through twelve** the HIV transitional care team completed the locator protocol at participant enrollment. The project leader provided ongoing coaching and problem-solving during biweekly staff meetings. The locator protocol was printed on brightly colored paper and included in new client enrollment packages. Either the case manager or the

community health workers (CHWs) completed the locator protocol at the bedside. Once the locator protocol was filled out, it was given to the designated CHW who followed the participant after hospital discharge. The CHWs used the locator protocol if a client missed a medical appointment or when the participant could not be found. The locator protocol was refined, and workflow issues resolved during the project period.

**Weeks 13 and 14** the project leader met with staff individually to discuss successes and challenges with using the locator protocol. Conversations included how to improve the locator protocol and recommendations for continued use.

### **Data collection**

New participants enrolled in the transitional care program were discussed at bi-weekly team meetings. The DNP team leader collected: 1) number of new participants, 2) number of completed locator protocols, 3) last contact with participant, 4) if the locator protocol was used to locate/communicate with a participant, 5) and if the locator protocol was effective in finding them. At the end of the project, staff met with the DNP team leader about the tool's usefulness and suggestions for improvements.

Participant outcomes measured included: 1) number (percentage) of participants who followed-up (engaged in care = completed one HIV care apt within 90 days of enrollment), 2) number (percentage) of participants found using locator protocol, 3) number of found patients who subsequently engaged in care, 4) number (percentage) of participants found who were unable/unready to return to care. In addition, the DNP student calculated baseline lost to follow ups (12-week reference) before initiation of locator protocol. Population demographic information (race, ethnicity, age, sex/gender, education and income) was extrapolated from chart reviews.

**Data analysis**

Descriptive statistics to describe population demographics, included the percentage of participants engaged in care, percentage lost to follow up.

**Measures to protect human subjects**

Participants enrolled in the transitional care program give consent for collection of personal information. The data is stored in the electronic medical record and only program staff or medical providers of the participants have access to the electronic charts. A description of the project was submitted and approved by the University of Maryland Baltimore (UMB) Institutional Review Board (IRB) as Non-Human Subjects Research (NHSR).

**Sustainability plan**

The locator protocol has been added to the electronic medical record. The locator protocol is now included all new patient packets and is part of staff's work plans.

**Results****Demographic data**

During the QI project period, twenty PLWH signed up for the transitional care program. Of the twenty participants, seventeen had a locator protocol completed by a staff member. As noted in Table 1, participant ages ranged from twenty-seven to sixty-six years old. The average age was forty-eight. All participants were African American, ten females (59%) and seven males (41%). Most participants were between 46-60 years old (n=7, 41%).

Comorbid conditions of participants included substance use (n=15, 88%), a mental health diagnosis (n=11, 65%) and unstable housing (n=9, 53%). Ten (59%) participants had substance use and a mental health diagnosis. Eight (47%) had both substance use and unstable housing.

Four (24%) participants had substance use, a mental health diagnosis and unstable housing (See Table 2).

### **Results of Implementation**

Of the twenty possible participants who were enrolled at the time of the project, seventeen had a completed locator protocol. Of the three clients without a completed locator protocol, one refused to complete it, one was discharged from the hospital before a CHW could meet with the participant. The other client was still hospitalized.

Of the 17 participants with locator protocols, 76% (n=13) were actively engaged in care defined as completing scheduled medical visits and staying in touch with the community health worker within the 90-day program. Clients were frequently lost and then found again with the locator protocol, but staff were not consistent with documenting what component of the locator protocol was useful in finding the client, or the number of clients found using the locator protocol in the electronic medical records. Bi-monthly informational interviews with the community health workers revealed they used a variety of ways to find their clients including accessing information in the locator protocol such as calling the client or emergency contact's phone numbers and visiting the clients local hang-outs and neighborhoods.

Unfortunately, one participant committed suicide while enrolled in the transitional care program due to a long-standing mental health condition. Three others were lost to follow-up who had concurrent substance use and unstable housing. Since completion of the QI project, the staff continues to complete the locator protocol at the bedside with new participants and uses it when trying to locate someone.

### **Changes in practice**

There were two change in practice during implementation. The transitional care team embedded the locator protocol in the electronic medical record. Early in the project, the staff realized that the locator protocol could also be used by clinic doctors and in-patient medical teams when patients were re-admitted to the hospital. The CHWs transcribed the paper locator protocol answers into the electronic medical record and then filed the original copy into the participant's paper chart.

The staff completed the locator protocol on several of their clients who were enrolled prior to the QI improvement start date. The CHWs noted the information collected on the locator protocol would be helpful to have for their most difficult clients who are frequently lost to follow-up. This change in practice was spontaneous without the influence from management. The most helpful aspects of the locator protocol per one CHW, "is that it's easy to complete and gives us helpful information about where to find a client."

### **Unintended consequences**

Initial conversations with staff about implementing the locator protocol were met with resistance. The case manager and community health workers thought the protocol would take too long to complete and be too burdensome to the existing workflow. In addition, the CHWs thought the expectation to find someone after a missed HIV appointment or lost to contact via telephone would be too time consuming. After lengthy discussion, the CHWs decided it should be their responsibility to complete the locator protocol at the bedside before the participant was discharged from the hospital. Up until this point, management had not been able to get the CHWs to meet their new clients in the hospital but instead would meet them in the clinic or home setting.

The transition care team took ownership of the locator protocol once the CHWs recognized it was helpful to meet their new clients before hospital discharge and that their clients would answer the personal and detailed questions. One CHW found the locator protocol helpful because she had the participant's case manager name and number at a local clinic. "The case manager would call me (CHW) whenever she had my client in her office, so I could speak with her."

### **Discussion**

This quality improvement project demonstrated that a completed locator protocol improved engagement in the transitional care program. Frequently, the locator protocol was used to find a client and re-engage them in care. The preliminary results find that up to 76% of clients with locator protocols are engaged in care during the program period as opposed to 50% prior to use of the locator protocol. This QI project supports the relationship between client engagement and use of a standardize protocol for lost to follow-ups results in reengagement in care as suggested in similar studies (Keller, et al., 2016 & Thomson, Cheti, & Reid, 2011)

There were no identified differences between observed and anticipated outcomes. There was exceptional buy-in from the CHWs and supportive management to complete the locator protocol. Team meetings consisted of identifying clients not engaged in care and steps to re-connect with them using the locator protocol as a guide. The strengths of the project included the seasoned staff and management team, ease to complete the protocol and acceptability by participants to answer the questions on the locator protocol. Initially the CHWs and case manager were overwhelmed with the idea of completing the locator protocol with every patient; they quickly adapted, took ownership of it and found the tool useful to them. The staff were

excellent at creating relationships with their clients and the locator protocol gave them an extra tool to maintain contact with clients.

There were limitations to this quality improvement project. First, the data was collected from a small number of participants who were HIV+, had a recent HIV related hospitalization, were out of medical care greater than six-months and either were experiencing unstable housing, substance use and/or had a poorly controlled mental health disorder and lived in an urban setting. Thus, the results may not be applicable to other HIV + individuals with different circumstances. In addition, the locator protocol was part of a larger project to keep clients engaged in care post-hospitalization. The project included 90-days of case management by community health workers, nurse case managers, social work, connections with local HIV out-patient clinics and resources for housing, mental health and substance. It is doubtful the locator protocol would be as helpful and beneficial without the support of the bigger program.

Second, documentation of how each client was found or exactly how often the protocol was used by staff was often missing in the electronic medical record. It would be helpful to know details about how much work went into finding clients who were lost and then found. To compensate for the lack of quantitative data; qualitative staff interviews were completed to understand the usefulness of the locator protocol. Project success was measured by how many more clients were engaged in care with a locator protocol verse without.

Third, the transitional care team is more seasoned, with standardized work-flow protocols, and regular staff meetings to better manage clients enrolled in the transitional care program compared to a year before. As a result, it is more difficult to say that the locator protocol was the reason for the success of client retention. Results could be confounded by the experienced staff, clearly defined program guidelines, and greater understanding of the

transitional care program by local HIV providers who see the clients. And finally, because of the brief QI period, it lacked analysis of clients who were retained in HIV care during the 90-day intervention resulted in initiation of cART and lower viral loads.

### **Conclusion**

Preliminary results suggest the locator protocol was effective in keeping in touch with clients and finding them when lost to follow-up. The staff is enthusiastic about the tool and continues to use it. Retention in the 90-day program has improved and staff verbalize pride in their ability to keep clients engaged. The locator protocol was integrated into the electronic medical record and added to staff work-flow.

There is potential to spread the use of the locator protocol to other contexts because the standardize locator protocol made it easy for staff to implement and utilize. The exact wording of the questions may need to be modified depending on the population but the foundation of using the tool at program enrolment is helpful in care retention. Since this QI project was small and only covered a short period of time, it would be helpful to implement across a larger population and in multiple sites to see if the results would be similar. Replication of the project could have positive results for similar populations with multiple challenges to managing their health and staying engaged with the health care system. Populations experiencing unstable housing would benefit most from this tool because it asks specific questions about where people spend their time and how best to find them.

Suggested next steps to study the usefulness of the locator protocol include coordinating with interested institutions to implement the tool on a larger scale. Plans include conference calls and grant writing for a larger study to explore the role of a locator protocol in retention in care and long-term outcomes including implementation of cART and viral load suppression.

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Table 1

Demographics of participants in transitional care program with completed locator protocols

|        | n=17 | %   | Range | Mean      |
|--------|------|-----|-------|-----------|
| Age    |      |     | 24-66 | 48 (13.3) |
| <30    | 3    | 18% |       |           |
| 31-45  | 4    | 24% |       |           |
| 46-60  | 7    | 41% |       |           |
| 61-66  | 3    | 18% |       |           |
| Gender |      |     |       |           |
| Male   | 7    | 41% |       |           |
| Female | 10   | 59% |       |           |

Table 2

Comorbidities of participants in transitional care program with completed locator protocols

|   | n  | %   |
|---|----|-----|
|   | 17 |     |
| Substance use   | 15 | 88% |
| Mental health diagnosis                                   | 11 | 65% |
| Unstable housing  | 9  | 53% |
| Substance use and mental health diagnosis                 | 10 | 59% |
| Substance use & unstable housing                          | 8  | 47% |
| Mental health diagnosis & unstable housing                | 5  | 29% |
| Substance use, mental health diagnosis & unstable housing | 4  | 24% |

**Evidence Review Table: Homelessness and HIV Care**

| Author, year        | Study objective/ intervention   | Design            | Sample (N)   | Outcomes studied (how measured)   | Results   | Level & Quality Rating |
|---------------------|---|-------------------|--|---|---|------------------------|
| Aidala et al., 2018 | Systematic review of housing, medical care and health outcomes of people living with HIV (PLWHIV) | Systematic review | Identified 152 studies: 2 RCT, 64 cohort or case-control, 86 cross-sectional studies between Jan 1, 1996 & March 31, 2014. | Examined the association between housing, medical care and health outcomes PLWHIV | <p>Unstable or inadequate housing &amp; homelessness assoc c diff utilization of HIV care, poorer tx outcomes &amp; higher HIV transmission rates</p> <p>Housing improves access &amp; retention in care and improves health outcomes. Housing affects: HIV healthcare access &amp; utilization, adherence</p> <p>HOUSING affects HEALTH (mental and physical)</p> <p>The worse the housing (stability, structure or quality) = poorer access to &amp; engagement in healthcare, lower adherence to ARV, worse health outcomes, higher ED &amp; inpatient use, higher rates of HIV risk behaviors.</p> <p>Homeless c AIDS more likely to delay or never start ARVs.</p> <p>HIV+ &amp; IVDU c stable housing= double odds of ARV meds vs no housing.</p> | 1A                     |

|  |   |   |   |  |  |    |
|--|---|---|---|--|--|----|
|  |   |   |   |  | Interventions that include housing for the homeless have better health outcomes, reduced transmission rates of HIV, & reduced HIV health disparities.  |    |
| O'toole, Johnson, Borgia, & Rose, 2015 | Multi-center, prospective community-based intervention with homeless veterans | RCT   | 185 homeless Veterans.  | Receipt of primary care within 4 weeks of study enrollment               | <p>Outreach intervention including a personal health assessment and brief intervention:</p> <p>Homeless Veterans can be engaged in primary care.</p> <p>The personal health assessment included extensive shelter and social support questions which were helpful in finding Veterans at risk for lost to follow-up</p>  | 1A |
| Thomson, Cheti, & Reid, 2011           | Implementation of an active tracing system to find lost to follow-ups         | Retrospective, descriptive analysis of routinely-collected program data | <p>1066 tracing activities in 3 MSF clinics between April 2008 and March 2009</p> <p>Kibera, informal settlement on outskirts of Nairobi. One of the largest slums in Africa c impoverished conditions and limited infrastructure</p> | Active tracing improve retention in care and decrease lost to follow-ups | <p>Traced participants consented to providing detailed personal contact information (#phone, address, places frequented, and social support contacts if person can't be reached)</p> <p>Nearly 60% of tracing activities resulted in patients returning to clinic.</p> <p>Patient final outcomes: 1. Confirmed dead, 2. Came back to clinic, 3. Admitted to hospital, 4. Went to another health structure, 5. Refused to come back to clinic, 6. Unable to come back to clinic, and 7. Unable to find.</p> | 3A |

|                       |  |                   |   |  |  |    |
|-----------------------|--|-------------------|---|--|--|----|
|                       |  |                   | & services.<br>Highly transient population d/t economic instability.  |  |  |    |
| Metsch et al., 2008   | HIV transmission risk behaviors for persons linked to care   | RCT               | 308 HIV + persons from 4 urban centers in the US<br>Inclusion criteria: HIV +, out of care (OOC), tx naïve, >= 18 yrs/old | Demographics<br><br>Self report of unprotected vaginal or anal intercourse<br><br>Mean # of outpatient visits for HIV patients | 73% were >30yr/old; 59% male; 26% black; 9% Hispanic; 6% white; 57% had a high school diploma; 71% made <\$10,000/yr. 64% heterosexual; 50% depressed; 17% use cocaine; 27% IDVU; 80% dx within 1yr; odds of sexual risk at if engaged in care was ½ that at baseline, OR, 0.54; P= .007; 50% less like to engage in risk behavior in previous month, compared to those c <3visits (OR, 0.53; P= .03.<br><br>Study had 97% follow-up at either 6- or 12-month assessment and were included in the analysis. No details about LTFU or missing date. | 1A |
| Mugavero et al., 2010 | Summary of retention measures to provide common nomenclature | Literature review | Synthesis of 5 commonly used measures of retention in HIV care  | Missed visits<br>Appointment adherence<br>Visit constancy<br>Gaps in care<br>HRSA HAD medical visits                           | Missed visits: easy to measure, widely used, limitations: crude measurement, not include denominator or variable # of scheduled visits; used for short term tracking.<br><br>Appt adherence: # completed visits/# scheduled visits. Easy to measure. Doesn't include cancelled visits; used for long term tracking   | 5A |

|                     |  |                      |  |  |  |    |
|---------------------|--|----------------------|--|--|--|----|
|                     |  |                      |  |  | <p>Visit constancy: # of 3month pds c &gt;= 1 completed visit: better accounts for loss to follow-up. Computationally more challenging. Used in research.</p> <p>Gaps in care: &gt;6months between visits. Easy to measure. Pts LTFU will have an undefined gap. Used in admin tracking</p> <p>HRSA HAB clinic visit: &gt;=2 visits in 12 months separated by &gt;= 3 months. Only need to capture completed visits. More challenging computationally. Useful in planning for local, regional and national payers and MCO.</p> |    |
| Keller et al. 2017. | Implementation of a clinical based retention protocol for patients OOC. Special Projects of National Significance Initiative | Dev & implementation | N=452. CAREWare report OOC pts and lists. Pt navigators and medical case managers used retention protocol to reengaged PLTFU |  | <p>Pt outcomes n=452:<br/>                 Active (reengaged in care) 194 (43%).<br/>                 Relocated 82 (18%).<br/>                 Incarcerated 18 (4%).<br/>                 Deceased 8 (2%).<br/>                 Unknown – not found and referred 150 (33%).</p> <p>Define Out of Care: Pts not seen in 9 months.</p>   | 6B |

## Appendix A

## Definitions

- Linkage to care is established by completing one HIV clinical care appointment within six months after index encounter with the patient. This is the urban hospital and HIV transitional care team's retention measure (M. Moen, personal communication, June 6, 2018).
- In care is one medical visit each 6 months within 24-month measurement period, with at least 60 days between the visit in the previous 6-month period to the visit in the subsequent 6-month period (Yehia, et al., 2012).
- Retention in care is defined by completing two HIV clinical care appointments at least 90 days apart within 12 months after index encounter. This is the HRSA medical visit performance measure (HRSA, 2018).

Appendix B

LOCATOR PROTOCOL

NAME: \_\_\_\_\_ ALIASES: \_\_\_\_\_ DATE OF ENROLLMENT: \_\_\_\_\_

YOUR ADDRESS: \_\_\_\_\_

OTHER ADDRESSES WHERE YOU STAY SOMETIMES? \_\_\_\_\_

GOOD NUMBER TO REACH YOU? \_\_\_\_\_

ANY OTHER PHONE NUMBERS TO REACH YOU? \_\_\_\_\_

WHEN YOU ARE NOT AT HOME WHERE DO YOU HANG OUT? \_\_\_\_\_

YOU ARE VERY IMPORTANT TO US. WHO ALWAYS KNOWS WHERE YOU ARE?

\_\_\_\_\_

WHAT'S THEIR PHONE NUMBER? \_\_\_\_\_ AND ADDRESS: \_\_\_\_\_

DO YOU HAVE A MAILING ADDRESS? \_\_\_\_\_

DO YOU CHECK IN REGULARLY? \_\_\_\_\_

DO YOU FREQUENT SHELTERS? Y/N

IF SO WHICH ONES: \_\_\_\_\_

DO YOU EVER VISIT SHELTERS OUTSIDE OF BALTIMORE CITY? Y/N

IF SO WHICH ONES: \_\_\_\_\_

ARE THERE MEAL PROGRAMS THAT YOU GO TO? Y/N

IF SO WHICH ONES: \_\_\_\_\_

ARE THERE ANY AGENCIES OR BUSINESSES YOU FREQUENT?

LIBRARIES: \_\_\_\_\_

METHADONE CLINIC: \_\_\_\_\_

DROP-IN CENTERS: \_\_\_\_\_

BARBER SHOP OR BEAUTY SALON: \_\_\_\_\_

ARE YOU CURRENTLY ON PAROLE OR PROBATION? \_\_\_\_\_

WHAT NEIGHBORHOOD DO YOU SPEND TIME IN? \_\_\_\_\_

WHAT ARE YOUR PLANS AFTER YOU LEAVE HERE? \_\_\_\_\_

IF PATIENT IS LOST TO FOLLOW-UP:

1. CALL ABOVE PHONE NUMBERS:

- Completed: Yes: \_\_\_\_\_ No: \_\_\_\_\_

2. VISIT ADDRESSES:

- Yes: \_\_\_\_\_, No: \_\_\_\_\_,
- NEIGHBORHOODS: Yes: \_\_\_\_\_, No: \_\_\_\_\_
- AGENCIES OR BUSINESSES THEY FREQUENT: Yes: \_\_\_\_\_, No: \_\_\_\_\_
- DIALYSIS CENTERS: Yes: \_\_\_\_\_, No: \_\_\_\_\_
- Other: \_\_\_\_\_
  - Yes: \_\_\_\_\_, No: \_\_\_\_\_

3. DATABASES TO FIND SOMEONE:

- INMATE LOCATOR FOR MD: <https://www.dpscs.state.md.us/services/inmate-locator.shtml>
  - Completed: Yes: \_\_\_\_\_, No: \_\_\_\_\_
- HOMELESS MANAGEMENT INFORMATION SYSTEM (HMIS)
  - Completed: Yes: \_\_\_\_\_, No: \_\_\_\_\_
- CRISP
  - Completed: Yes: \_\_\_\_\_, No: \_\_\_\_\_

