Data Integration Grant
Retention in HIV Care & Community Viral Load Suppression Protocol

Background

The updated 2015–2020 National HIV/AIDS Strategy guides ending the US HIV epidemic. Its goals are to (1) reduce HIV infections, (2) increase access to care and improve health outcomes for people living with HIV, (3) reduce HIV-related health disparities and health inequities, and (4) achieve a more coordinated national response to the HIV epidemic.

As part of the Data Integration Project (DIG), the City of Hartford and community partner AIDS Connecticut as well as HIV medical and supportive service providers from the Hartford Transitional Grant area have reaffirmed commitment to providing services to our consumers in alignment with the goals of the National HIV/AIDS Strategy, using integration of data programs CAREWare and Caseworthy (HMIS). In 2017, the Centers for Disease Control and Prevention (CDC) announced that HIV+ individuals who sustain suppressed or undetectable viral loads are effectively unable to transmit HIV infection to sexual partners. The term “viral load” refers to the number of copies of HIV viral per milliliter (mL) of blood. VL suppression is achieved through the successful administration of combined antiretroviral therapy (cART, also referred to as “Highly Active Antiretroviral Therapy” or HAART) and measured by blood test. As of the date of the protocol, undetectable or suppressed VL is defined as <200 copies/mL.

Also in 2017, the Undetectable=Untransmittable (U=U) campaign was born and organizations around the country began educating People Living with HIV/AIDS (PLWHA) and their sexual partners about the importance of viral load suppression and cART compliance. For many people, U=U offers new found hope and freedom to open social, sexual, and reproductive choices that they may have thought impossible. Moreover, U=U reduces stigma, encourages healthy behaviors, and offers a strong argument for universal access to treatment, bringing us closer than ever to ending the HIV epidemic. The DIG Committee members are involved in several community efforts and roundtables which support bringing U=U to the forefront of discussion as well as opening doors for advocacy, research, and education so that this message can reach the individuals it was intended to benefit. The City of Hartford and others have signed on as a U=U community partner as well as participating in the “Getting to Zero” commission, a coordinated statewide public health effort to end HIV in Connecticut.

A 2014 National Institutes of Health study demonstrated that retention in care is very closely related to viral load suppression, especially for patients with lower CD4 counts. Another study, “Retention in Continuous Care and Sustained Viral Suppression: Examining the Association


1
among Individuals Living with HIV” concluded that persons retained in care were three times more likely to sustain viral load suppression over time. Through these protocols, providers have clear guidance and information on how to assist patients in obtaining positive health outcomes.

**Community Viral Load (VL) Suppression Protocol (for providers)**

**Target:** HIV+ Individuals* with VL count greater than 200 copies/ml per laboratory report

**Goal:** To assist individuals living with HIV who have a VL >200

*For the purposes of the protocol, a newly diagnosed individual has received HIV+ diagnosis within the previous 12 months

**Assessment**

- **Level of Health Literacy**
  - Many newly diagnosed individuals do not have the proper information or support to access care or understand the importance of medical treatment or the consequences of delaying or avoiding care. It can be especially problematic for individuals who “feel good” to
  - Many PLWHA have limited understanding of HIV, how it works in their body, and why it is important to take medication. The provider should take time to explain HIV life cycle and how medication works in a non-judgmental manner and ensure that the individual understands. Providers should be versed in techniques such as Motivational Interviewing and “Teach Back or Show Me” methods.

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• **Engagement with medical care**
  - Newly diagnosed: Depending on when and where a person gets tested, they may or may not be connected with a medical professional immediately or not understand the importance of working closely with their provider.
  - Most PLWHA understand the importance of working with a doctor. Not everyone has the same level of engagement with their care provider. There may be a number of factors that affect an individual’s participation in their care.
  - PLWHA who are new to the area may be unfamiliar with the care continuum, including lack of knowledge of how or where to access HIV medical treatment.
  - PLWHA are unique in their belief system and trust of medical providers may vary making engagement with providers inconsistent.

• **Prescribed cART**
  - Newly dx: The pharmacy, insurance to cover prescriptions, and medical care systems can be hard to navigate. It is important to assess the clients’ level of understanding of the healthcare delivery system.
    - Newly diagnosed clients usually have tests from their doctor to determine which medications will work for his/her virologic profile. This is typically referred to as a “genotypic assay” or “resistance” test. This tests looks at mutations in the virus and measures resistance to different classes of ART.
    - If a client’s treatment is deferred by a doctor, coordinate with MD to find out why and when they are planning to start treatment.
  - If the client has been prescribed medications, the client may not have filled their prescription or picked it up at the pharmacy.
  - It is important for the MCM to communicate with care providers and pharmacy regarding testing and pharmacy pickups.
  - If the client has been prescribed cART, picked up medications, etc. client may have compliance issues. Ask questions such as, “When was the last time you missed a dose of HIV medication?”; “How do you remember to take your medications every day?”
  - Clients with compliance issues should be referred to a treatment adherence nurse for ongoing support.

• **Barriers to care**
  - Newly diagnosed: Receiving an HIV+ diagnosis can cause a range of reactions and emotions. Depending on the individual and unique circumstances, recently diagnosed individuals may delay treatment for a variety of reasons.
  - Socioeconomic status (poverty) is a social determinant of health. People who experience
  - Where a client resides and ability to access treatment effectively and safely can impact engagement in care
  - Competing life priorities: work, children, substance use, mental health issues
Action Steps

- Assess HIV health literacy, engagement with care and possible barriers to care, if prescribed cART, level of compliance.
  - HIV Health Literacy – if client demonstrates poor health literacy, provide client ongoing education and support monthly, reassess every six months as necessary
  - Prescribed cART – If client has been prescribed medication to treat their HIV and haven’t started, ask appropriate questions and provide support to client. Offer referral to TA nurse and do warm handoff if possible. Follow up with client monthly until ART is initiated
  - Barriers – the barriers to care that a client can experience are diverse. MCM should work to identify and eliminate potential, perceived, and real barriers to care through support, education, referrals and collaboration. There is not a one size fits all solution for barriers and client level of motivation, input, and resources should be considered when making any plan to assist the client in addressing barriers. After referrals are made, the MCM should continue to monitor the clients’ progress to achieving goals by using the clients’ care plan and progress notes
  - Engagement with care – (Also refer to Retention in Care Protocol) collaboration with medical providers is of the utmost importance. Identify clients’ care teams, including personal supports and build partnerships with the clients’ providers and support network. If the client is out of care and you have not seen them, follow-up with providers to see when the last time they were seen and contact emergency contact if the client has given you permission in writing. Send a client a letter if possible if they do not respond to phone contact. If you are unable to contact the client after reasonable attempts, a referral to EIS (if there is an ROI) is appropriate in this circumstance.
Client with >200 VL

No cART
- Coordinate with MD & Pharmacy
- Provide Education & support on starting ART
- Refer to TA nurse for continuing education support

Barriers to care
- Assess barriers to care
- Add to care plan according to client preference, make referrals as necessary

Level of engagement in medical care
- Client engaged in care
  - Continue coordinating care with medical providers
- Client sporadically compliant
  - Identify barriers, make referrals as necessary, provide appointment reminders, schedule transportation, etc.
- Client out of care
  - If you have contact with client, encourage and support care. Offer to help client find new provider
  - If no contact, refer client to EIS program for location and reengagement

Low health literacy
- Provide education and support, repeat as necessary, refer to TA nurse if client agreeable
Retention in Care Protocol

Target: HIV+ individuals who have missed Medical Care, Oral Health Care, Substance Use, Mental Health Services and Medical Case Management Services.

Goal: To retain HIV+ individuals in care and to engage those who are lost-to-care back into consistent HIV care.

Referral Method: Decided to utilize CAREWare - Required software for Ryan White sub-recipients in CT. Allowed for electronic referrals between providers that share the same client in different medical sites/clinics/agencies.

Determining Out of Care/Lost to Care: On the first day of the month, medical sites/clinics/agencies run a list of out-of-care clients (CORE 1 measure for medical care; Missed appointment for oral health, substance use, mental health and medical case management) Program staff runs the CORE 1/Missed Appointment list through clinic EMR, CAREWare (CW) or Client records.

(List should be checked to remove clients who are not truly out-of-care due to special circumstances or who have upcoming appointments).

Early Intervention staff, (EIS) receive list from clinic/medical sites/agencies via an electronic CW referral

EIS staff work on locating client for roughly 30 days

- After 30-day time period of locating, EIS staff document efforts and provide outcomes via CAREWare
- Clinic closes out clients who have been located or a definitive outcome has been documented. Outcomes documented include:
  - Re-engaged in care at referring provider
  - Re-engaged in care with new provider
  - Deceased
  - Re-located
  - Incarcerated
  - Located, not re-engaged in care to-date
  - Unknown-not located

*“Unknown, not located” clients and “Located, not re-engaged in care to-date” clients referred to State Disease Intervention Specialist for state-level follow-up/field work
**CW OUTCOME DEFINITIONS**

- Re-engaged in care at referring sub-recipient
- Reengaged in care with new provider
- Incarcerated—The client is disenrolled from the program because he or she is serving a criminal sentence in a Federal, State, or local penitentiary, prison, jail, reformatory, work farm, or similar correctional institution (whether operated by the government or a contractor).
- Relocated—The client is disenrolled from the program because he or she has moved out of the agency’s service area.
- Located, not reengaged in care to-date—The client was located, but was not reengaged to care, because he or she may not be ready to be re-engaged into care.
- *Unknown-not located ---The Early Intervention staff was unable to locate the client at the 30 date time line.
- Deceased