Data to Care Protocol

Context:
Persons living with HIV (PLWH) who are not in care are at a greater risk for poor health outcomes, premature death and transmitting HIV. The purpose of "Data to Care" (DtC) is to use HIV surveillance data to identify PLWH who are not in care, link them to care, and support the HIV Care Continuum. Historically, HIV surveillance data has been used to monitor and characterize the HIV epidemic both locally and nationally. DtC reflects a shift from the typical use of HIV surveillance data to using the data to improve health outcomes for PLWH. The ultimate goals of DtC are to increase the number of PLWH who are 1) engaged in HIV care, and 2) have an undetectable viral load.

The DtC Initiative utilizes the Care Markers Database (CMDB) to create lists of people who appear to be out of care (OOC) within a specified time frame. Once a list has been produced, the Division of Disease Prevention (DDP) will transmit information securely to the DtC Linkage Coordinator, Disease Intervention Specialists (DIS), designated personnel at local health departments (LHDs), medical sites or community-based organizations (CBOs) that provide re-engagement and linkage services. The lists that are generated for all sites will **only** include clients who have had a documented relationship with that facility, with the exception of the DIS and DtC Linkage Coordinator. This document specifies a protocol for personnel to contact OOC individuals.

Prior to beginning follow-up of OOC persons all staff will be trained on the DtC protocol, data collection tool and the process of reporting data collected during follow up. This training will detail the DtC process including paper flow, expectation of tasks, and contact persons within DDP.

1. Generating the OOC List

This refers to the period prior to distribution of any OOC list. Activities during this stage will allow DDP to identify the most up-to-date client contact information available prior to lists being released for follow up.

Eligibility

Clients are eligible for the OOC list if they are:

1. HIV-positive and reported to the HIV Surveillance database (eHARS);
2. 18 years of age or older;
3. Living with a last known address in Virginia
4. Meet the OOC Definition:
    a. Have evidence of care via a reported care marker in the reference year but no evidence of care within one year (365 days) from the date that the OOC list was generated. For example: Clients would only be considered if they had evidence of care in 2015 as the reference year. If the OOC list was generated on 12/31/2016, clients who do not have a care marker reported from 12/31/2015-12/31/2016

would appear on the OOC list. Care markers are considered to be any of the following occurring on or after the day of HIV diagnosis:

a. CD4 count
b. Viral Load
c. HIV medical care visit
d. Antiretroviral therapy (ART) prescription

2. Client Follow-up

1. OOC Lists:

a. **Time Frames**: The maximum duration for agencies to investigate each client on an OOC list is 60 days per client. Agencies should submit the DtC forms to VDH as soon as they are complete. OOC Lists will be generated every 6 months for each site.

b. **Number of Clients on Lists**: For agencies with an OOC list with more than 50 persons, the list will be distributed in increments of 50, as to not overburden agency staff. Lists may be distributed in increments of fewer than 50 based on review and discussion with the participating site and VDH. After the DtC forms for the first 50 persons on the OOC list are returned to VDH, the remaining persons on the list will be distributed (also in increments of 50).

c. Distribution:

i. DDP will provide agencies with the most up-to-date client contact information available that may be needed to conduct follow up for clients on the OOC lists. Each client will be assigned a unique ID called a Data to Care number that will be entered on the DtC form. This unique ID does not contain any personal health information (PHI) and will be used to track forms as they are received at the health department and entered into the CMDB. Additionally, the name of the facility completing the DtC activities is required to be entered on each DtC Collection Tool.

ii. **All agencies (excluding Disease Intervention Specialists [DIS]):** Staff will be provided an Excel spreadsheet through a secured mechanism, along with a DtC Data Collection Tool (which is attached to the Coordination of Care and Services Agreement Form [CCSA]).

iii. **DIS Only:** DIS will be provided Field Records (FRs) and the DtC Data Collection Tool attached to the CCSA from the CRU Supervisor.

iv. **DtC Linkage Coordinator Only:** The DtC Linkage Coordinator will receive lists of persons who may not have ever engaged in care, have no provider information available or who were last in care at agencies that VDH does not contract with.

2. *Contact Attempts:*

a. **Number of Contact Attempts:** Staff will attempt to contact the client a minimum of three times, using methodologies consistent with that agency's standard

practices. Staff must exhaust all possible avenues until they either locate and speak with the client or determine that a client is deceased, has moved out of state, or is unable to be located.

b. **Contact Methods**: Staff should only use methodologies consistent with their agency's standard practices. Contact methods could include: review of internal medical records, phone calls, text messages, emails, letters, field visits, and social media.

i. Phone calls and texting may be continued if there are indicators that the phone number is in use by the OOC client (e.g. if the voicemail message indicates the name of the client) as long as the investigation remains open.

ii. Field visits should not be initiated before other contact attempts in order to inform the client that the agency or health department is attempting to contact the patient about a health related issue, and to expect a field visit if they do not respond.

i. Multiple field visits may have to be made at different times of the day if there is evidence that the client is living at the location.

ii. Investigators should attempt to make at least one face-to-face encounter with the client.

iii. **Staff should follow their agency's safety policies and procedures when conducting field visits.**

3. ***Data Collection Tool:*** Staff will use the DtC Data Collection Tool to document their progress in attempting to contact the client. Instructions for the DtC Collection Tool are included on the first page of the document. As a result of these attempts, staff will assign the client one of eight outcomes on the DtC Data Collection Tool (by the end of the 60 day time frame, if not sooner), as follows:

a. Client located and currently in medical care within last 12 months

i. This outcome should only be used if evidence of care can be verified by the medical provider; a date of medical visit is required for this outcome.

Note: If it cannot be verified that the patient is currently in care, then do not select this outcome.

ii. If the client has a scheduled upcoming appointment then provide the appointment date, name of medical facility, and name of medical provider, and phone number and address of the facility.

b. Client was located and not in care

i. Check the boxes associated with the barriers to care, or select other and specify if barrier is not listed.

ii. Currently in the process of reengaging (provide date of upcoming appointment)

iii. Want to reengage

1. Referred to patient navigator (provide name of navigator)
2. Referred to provider (provide name of provider)
3. Date of scheduled appointment

iv. Refused care

c. Client moved out of state (provide the state of current residence, current address, and month and year of move, if available)

d. Client is deceased (provide date of death and source of death information)

e. Client is incarcerated (provide facility name and expected date of release)
   i. If the client's expected date of release is within 6 months of the date the investigator has found the information, then the investigator must refer the client to CHARLI or Care Coordination.

f. Client was unable to be located

g. Client was discharged (provide date of discharge and what facility the client was discharged to)
   i. Do not contact the facility where the client was discharged to confirm
      1. This becomes a confidentiality issue

h. Other: (please specify)
   1. Select this outcome for any situation that does not fit any of the above outcomes. Examples: client was deported back to their country of origin and client was on the run from law enforcement.

4. ***Closing the Investigation:***
   a. If the client cannot be located, is located and in care, or is located and refuses services, staff can then close the case. Staff should complete the DtC Data Collection Tool, documenting contact attempts and appropriate outcome.
   b. If the client is located in Virginia, but outside the usual catchment area of the agency, staff will follow up according to methodologies consistent with that agency's standard practice.
      i. (**DIS Only:** DIS will work with the field supervisor to determine on a case-by-case basis if the investigation will continue.)

5. ***Coordination of Care and Services Agreement (CCSA):*** If the client is located and not in care, staff will ask the client to sign the CCSA, explaining that if the client experiences difficulty maintaining engagement with care in the future, signing the document will ease the process of providing assistance to get back in medical care.
   a. Clients who refuse to sign the CCSA should still be offered referrals to care.
   b. Updated client contact information should be recorded on the DtC Data Collection Tool.

6. Please direct all DtC questions to the contact information below and submit all completed DtC Data Collection Tools and CCSA forms to VDH:

Virginia Department of Health
Attn: Amanda Saia, HIV Surveillance Epidemiologist
109 Governor St Room 325-C
Richmond, VA 23219
FAX: (804) 864-7970
Phone Number: (804) 864-7862
Email: Amanda.Saia@vdh.virginia.gov

3. Security and Confidentiality:

The Virginia Department of Health (VDH) and Division of Disease Prevention (DDP) adhere to all security and confidentiality guidelines as outlined by the DDP Data S&C Policies and Procedures(http://www.vdh.virginia.gov/epidemiology/DiseasePrevention/documents/pdf/DDP_Security_and_Confidentiality_Policies_and_Procedures. pdf) and are compliant with the Health Insurance Portability and Accountability Act (HIPAA). Contracted agencies should strictly adhere to all confidentiality guidelines when working with protected patient information.

4. Referral to Care/Services (For DIS Only, Using Active Referral Protocol)

This stage in the protocol occurs simultaneously to stage two, and will be enacted as the DIS locates individuals who are not in care and agree to receive linkage services. Using the DtC data collection tool, the DIS will assess the client's barriers to care, as well as their need for other services. The DIS will then follow the steps of the Active Referral Protocol to link the client to the needed services. Once the client has attended their first medical visit, the DIS will transmit the DtC data collection tool and the completed CCSA to DDP. The DtC data collection tool will be kept in the secure file room next to the CCSA forms.