Utilizing HIV Surveillance Data to Reach Out-of-Care Persons: The Virginia Data to Care Project

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The Data to Care Initiative

❖ Data to Care (DtC) is a Centers for Disease Control and Prevention (CDC) national initiative to use HIV surveillance data to identify persons living with HIV (PLWH) who are not in care to link or reengage these persons into HIV medical care. [1]

❖ DtC aligns with the 2020 National HIV/AIDS Strategy goals to reduce new HIV infections and improve access to care and health outcomes.[2]

❖ The ultimate goals of DtC are to increase the number of PLWH that are 1) engaged in HIV care and 2) virally suppressed (<200 copies/mL).[1]

❖ The Virginia Department of Health (VDH) developed, piloted, and expanded a DtC program using HIV surveillance and other data sources to identify clients who are out-of-care (OOC) to improve health outcomes among PLWH.

❖ This initiative was a cross-unit, collaborative effort with Virginia's HIV Surveillance, Care Services, Prevention and STD Field Operations units.

Data to Care Definitions

Care Markers Database

• Contains information on care markers for PLWH from several sources, including HIV Surveillance, Ryan White, AIDS Drug Assistance Program, Medicaid, and others.

Care Markers

• Evidence of care via a CD4 count, viral load, HIV-related medical visit or antiretroviral therapy (ART) prescription.
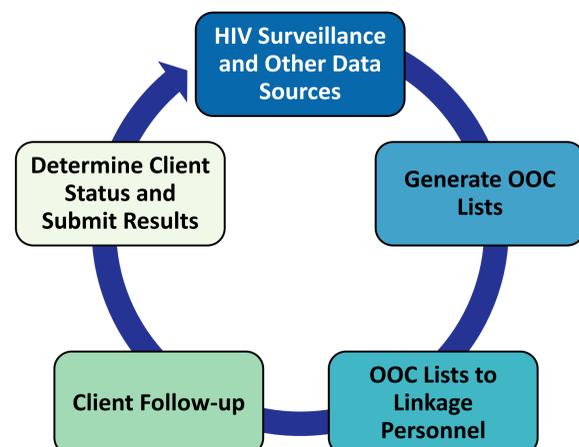
Enhanced HIV/AIDS Reporting System (eHARS)

• The main HIV surveillance database where all HIV case information and lab tests results are stored.

Out-of-Care (OOC)

• Clients must have a care marker reported in the reference year but no evidence of care in the following calendar year
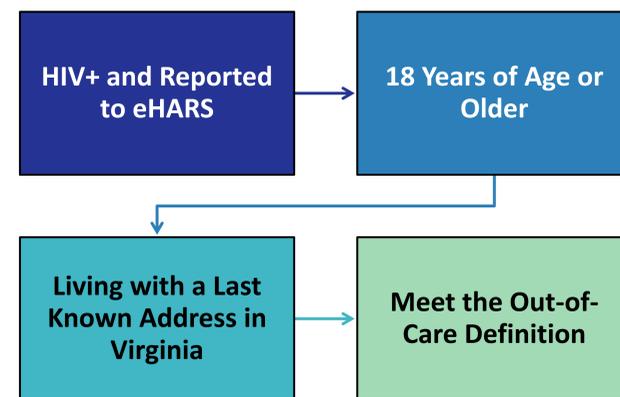
Figure 1: The Data to Care Process

HIV Surveillance and Other Data Sources → Generate OOC Lists → OOC Lists to Linkage Personnel → Client Follow-up → Determine Client Status and Submit Results → (cycle)

The Data to Care Process

❖ VDH developed a protocol to outline the entire DtC process, specifying time frames, sources of data, the OOC definition and internal data processes (Figure 1).

❖ The Care Markers Database and other data sources are used to generate OOC lists.

❖ OOC lists are disseminated to linkage personnel at local health departments, medical facilities and community-based organizations.

❖ Linkage personnel attempt to find information or locate OOC clients. The DtC data collection tool, which details the process used for each contact attempt and the client's current status/outcome, are submitted to VDH.

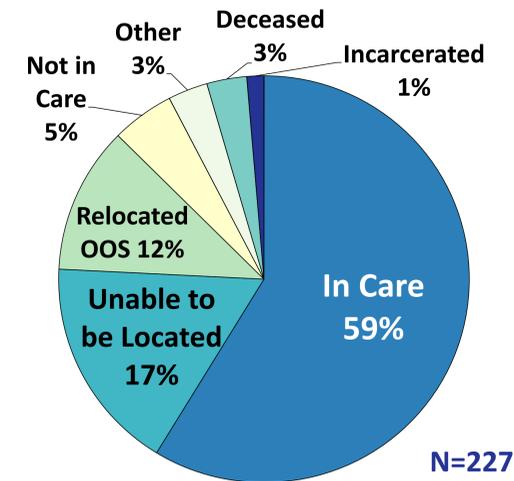❖ DtC results are used to update surveillance data, identify reporting issues, and help improve future OOC lists.

Out-of-Care List Eligibility Criteria

HIV+ and Reported to eHARS → 18 Years of Age or Older → Living with a Last Known Address in Virginia → Meet the Out-of-Care Definition

Data to Care in Virginia

❖ The DtC initiative was implemented in early 2015 with Disease Intervention Specialists (DIS) at five local health departments to locate and reengage OOC clients.

❖ The pilot was expanded to linkage personnel at six of VDH's contracted medical providers, community-based organizations, and local health departments that had Community Health Worker or Patient Navigation programs.

❖ Clients were considered to be OOC if they had a care marker in 2013 but no care in 2014 or had a care marker in 2014 but no care in 2015.

❖ **OOC List Dissemination:**
  ▪ **DIS:** OOC lists included a sample of clients with a last known address in the corresponding health district
  ▪ **Agencies:** OOC lists were generated using an algorithm that selected the last known agency the client received a care marker, and only included clients that had a previously documented relationship with that agency.

Figure 2: Data to Care Results

In Care 59%; Unable to be Located 17%; Relocated OOS 12%; Not in Care 5%; Other 3%; Deceased 3%; Incarcerated 1%; N=227

Discussion

❖ Preliminary results from the project's first year of implementation demonstrate lower numbers of PLWH who were truly "out-of-care" (Figure 2).

❖ Nearly 60% of clients were found to be in care, 17% were unable to be located, 12% relocated out of state (OOS) and 5% were not in care (Figure 2).

❖ Of the 11 persons "not in care", seven reengaged in care as a result of DtC efforts, evident by a reported care marker, and nearly 30% of those identified as "In Care" did not have a care marker reported following client follow-up (Figure 3).

Lessons Learned

❖ Client results and feedback from pilot participants and community stakeholders helped refine procedures and guide further DtC implementation and expansion.

❖ Integrating all available data sources more accurately depicts a client's care status and has helped prevent clients who are not OOC from being on the OOC list.

❖ Accurint (LexisNexis), the world's largest electronic database for legal and public-records related information, is a useful system for finding updated contact and vital status information
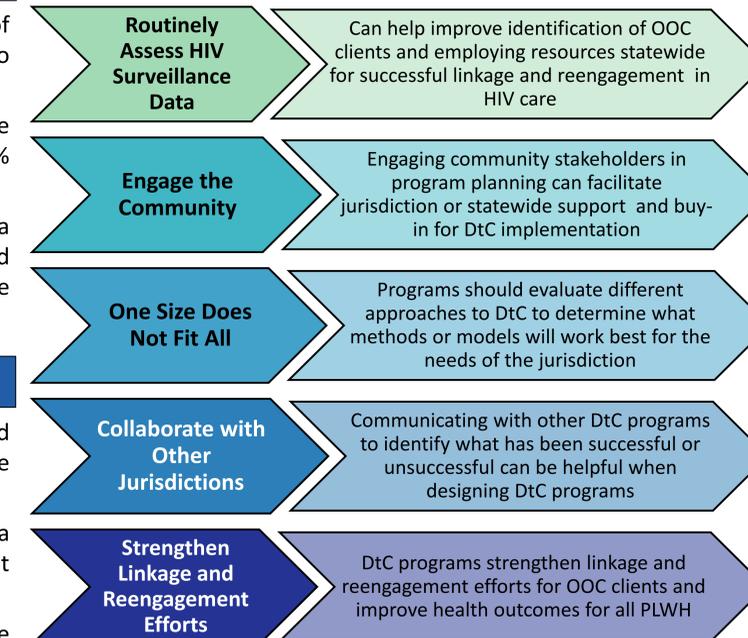
Figure 3: Results of Persons Identified as "Not in Care" and "In Care"

Not in Care: Refused Care 37%, Reengaged in Care 64%
In Care: Care Marker Reported 69%, No Care Marker Reported 31%
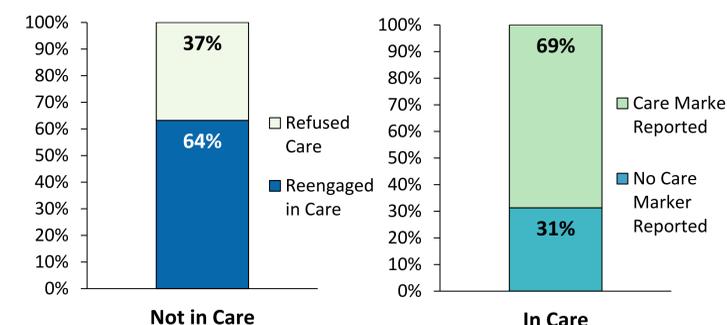
Current Activities and Next Steps

❖ The DtC project has been implemented statewide and is continuing to expand across Virginia, with more than 18 agencies participating in DtC efforts.

❖ As of April 1, 2016, DtC is a contractual requirement for all Ryan White (RW) Part B funded agencies in Virginia.

❖ VDH hired a DtC Linkage Coordinator, who will search for and locate OOC clients statewide, refer clients to linkage and reengagement services, serve as a resource for clients, and help empower clients to take an active role in their HIV care.

❖ VDH is developing a plan to import DtC results into eHARS and plans to address reporting issues that are identified through DtC.

❖ In 2017, an electronic-based DtC platform is planned to be implemented within Virginia's HIV Care and Prevention data system, e2Virginia.

Recommendations

Routinely Assess HIV Surveillance Data	Can help improve identification of OOC clients and employing resources statewide for successful linkage and reengagement in HIV care
Engage the Community	Engaging community stakeholders in program planning can facilitate jurisdiction or statewide support and buy-in for DtC implementation
One Size Does Not Fit All	Programs should evaluate different approaches to DtC to determine what methods or models will work best for the needs of the jurisdiction
Collaborate with Other Jurisdictions	Communicating with other DtC programs to identify what has been successful or unsuccessful can be helpful when designing DtC programs
Strengthen Linkage and Reengagement Efforts	DtC programs strengthen linkage and reengagement efforts for OOC clients and improve health outcomes for all PLWH

Acknowledgments

References

[1] Data to Care. Accessed at: https://effectiveinterventions.cdc.gov/en/HighImpactPrevention/PublicHealthStrategies/DatatoCare.aspx

[2] National HIV/AIDS Strategy: Updated to 2020. Accessed at https://www.aids.gov/federal-resources/national-hiv-aids-tsrategy/ nhas-update/index.html