Data to Care Strategies to Re-Engage People with HIV Who are Out of Care

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The findings and conclusions in this presentation are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Purpose

1. Overview of Data to Care strategies for re-engaging PWH who are not in care (NIC)

2. Data to Care steps and data sources

3. Data landscape lessons learned from NIC investigations

4. Next Steps

Background on Data to Care

Goals of Data to Care (D2C):

Identify persons living with HIV who are not in care (NIC)

Link them to care and appropriate social services

Ensure they are engaged in medical care and are achieving and maintaining viral suppression over the long term

D2C is a collaborative activity involving surveillance, prevention, health providers, and others.

D2C was required in PS18-1802 and one possible approach for required re-engagement activities in PS-24-0047.

Main Steps in Data-to-Care Not-in-Care Programs

- Step 1: Identification

- Step 2: Investigation

- Step 3: Linkage to HIV Medical Care

- Step 4: Monitoring Continuum of Care

- Step 5: HIV Prevention and Support Services

- Step 6: Feedback Loop

Key Components

- Collaboration between surveillance, prevention, and care providers and care programs

- Access to data sources

- Data Sharing and Data Sharing Agreements

- Program Tracking and Data Management

- Community Involvement

- Monitoring and Evaluation

Data to Care (D2C) Data Sources and Approaches

Programs using multiple or integrated disease surveillance systems appear more efficient at identifying persons who were truly not in care (NIC) and confirming care status.

Optimal integration of data sources dependent on local context.

Examples of Data Sources

eHARS, integrated health department systems

Partner services data, people search tools, DMV, deduplication activities for locating and identifying those out of jurisdiction

Vital statistics data to identify persons who have died

Approaches to Define NIC

Laboratory data (CD4 or Viral load), other laboratory (molecular or genotype data)

ARV prescription data, ADAP

Care visit data, Ryan White program data, Medicaid, HIE

Out of care definitions (e.g., <12 months without evidence of care)

Data to Care (D2C) NIC Indicators

ID — NIC IDENTIFICATION

Percentage of presumptively not-in-care PWH with an investigation opened (initiated) during a specified 6-month evaluation period, who were confirmed not to be in care within 90 days after the investigation was opened

L — LINKAGE

Percentage of PWH confirmed during a specified 6-month evaluation period not to be in care, who were linked to HIV medical care within 30 days after being confirmed not to be in care

VS — VIRAL SUPPRESSION

U=U

Percentage of PWH linked to HIV medical care during a specified 6-month evaluation period, who achieved HIV viral suppression within six months (180 days) after being linked to care

Systematic Review of Data to Care (D2C) Outcomes

The systematic review findings:

- More people were identified as confirmed NIC compared other HIV care statuses (e.g., current to care, deceased).

- Across the different analyses that measured either engagement or VS, findings were in the positive direction supporting D2C improving outcomes.

- Challenges include difficulty identifying true NIC population, timeliness of surveillance data, integration of data sources and collaborative models.

Roberts, KT et al Assessing the Effectiveness of Data-to-Care Strategies for Improving HIV Care Outcomes: A Systematic Review   (Pending Publication)

Data to Care (D2C) Program Highlights 2018-2022*

NIC IDENTIFICATION

A relatively small proportion
(< 20%) of presumptive NIC cases were confirmed NIC but data from this step provided valuable updates to surveillance and prevention data.
Most were confirmed within 90 days (over 80%)

LINKAGE

About a third (30%) of confirmed NIC cases were linked to care through HD intervention, and an additional 13% returned to care on their own
Most (81%) of those linked or relinked were linked to care within 30 days

VIRAL SUPPRESSION

U=U

Most people linked to care were able to achieve viral suppression within 1 year of linkage
(63% within 6 mos; 73% within a year)

* Unpublished preliminary results longitudinal analyses of Dec 2022 data; Individual program results vary.

Health Department Insights

Tool for Re-Engagement

Many health departments plan to continue or implement D2C

Integration of D2C type approaches into overall program efforts

People linked to care & achieving viral suppression

Improved relationships

Improved surveillance data quality

Benefits

Challenges

Multiple data sources needed to identify those truly out of care

Barriers to sharing data

Training and Guidance

Needs

Next Steps

- Continue technical assistance and guidance

- Capture more detailed information on program implementation

- Continue monitoring and evaluation

Resources

- https://www.cdc.gov/hiv/effective-interventions/treat/data-to-care/index.html

- https://www.cdc.gov/hiv/pdf/funding/announcements/ps24-0047/CDC-HIV-PS24-0047-Attachment-Data-to-Care-Program-Guidancex.pdf - This document provides background and general D2C program information for PS24-0047.

- https://www.cdc.gov/hiv/docx/funding/announcements/ps24-0047/D2C-Guidance.pdf - This document provides information on the D2C indicators and reporting requirements.

Below are some external resources that programs may want to consider to inform the strengthening and maintenance of their D2C programs.

- https://nastad.org/flipbook/?page=1 – This is the weblink to NASTAD's digibook "Data Points: A Health Department Roadmap for Enhancing Data to Care Programs". This web-based book contains more information about D2C, a 2015 assessment of D2C programs, and some examples from Health Departments. **

- https://nastad.org/data2care/ – This is the weblink to NASTAD's D2C site with companion information to the Digibook "Data Points: A Health Department Roadmap for Enhancing Data to Care Programs". Additional guidance and resources exist at this site on funding, staffing, data sharing, prioritizing, managing, monitoring, and evaluating D2C programs. **

 **** Disclaimer – These weblinks were sponsored by CDC's Division of HIV Prevention and are current as of June 5, 2024. Maintenance of these weblinks is the responsibility of the authorizing agency.**

Selected Journal Articles

- JAIDS supplement on Data to Care: Advancing Data to Care as a prevention strategy to reduce HIV morbidity and mortality in the U.S. Journal of Acquired Immune Deficiency Syndrome. 82:S1-S79, September 1, 2019

- Carey JW, Roland KB, Bessler PA, Tesfaye CL, Randall LA, Frew PM. Overcoming Challenges to HIV Medical Care-seeking and Treatment Among Data-to-Care Program Clients in Baton Rouge and New Orleans, Louisiana. J Assoc Nurses AIDS Care. 2022 Dec 16. PMID: 36524875. DOI: 10.1097/JNC.0000000000000375

- Elder H, Lang SG, Villanueva M, John B, Roosevelt K, Altice FL, Brady KA, Gibson B, Buchelli M, DeMaria A and Randall LM (2023) Using the exploration, preparation, implementation, sustainment (EPIS) framework to assess the cooperative re-engagement controlled trial (CoRECT). *Front. Public Health* 11:1223149. doi: 10.3389/fpubh.2023.1223149

- Mulatu MS, Carter JW, Flores SA, et al. Expanding data to care programs to improve HIV care continuum among men who have sex with men and transgender persons: Key processes and outcomes from Project PrIDE, 2015-2019. Public Health Rep. 2023 Jan-Feb; 138(1): 43-53.

- Neblett Fanfair R, Khalil G, Williams T, et al. The Cooperative Re-engagement Controlled Rial (CoRECT): A randomized trial to assess a collaborative data to care model to improve HIV care continuum outcomes. Lancet Reg Health Am. 2021 Aug 28:3:100057.

- Roland KB, Carey JW, Bessler PA, et al. "Take care of their hierarchy of needs first": Strategies used by data-to-care staff to address barriers to HIV care engagement. AIDS Care. 2023 May; 35(5):764-771

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Thank you!

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