

Integrating HIV Surveillance and Prevention Programs to End New Cases of HIV: A Resource Document from CSTE and HealthHIV

INTRODUCTION

During July–September 2019, the Council of State and Territorial Epidemiologists (CSTE) and HealthHIV conducted an interactive learning series for state and local HIV prevention and surveillance staff to support increased integration and collaboration. A needs assessment identified the following topics as being potentially most useful to participants: data to care, effective use of data to support programs, HIV cluster detection and response, and the expanding role of disease investigation specialists (DIS). CSTE and HealthHIV then identified subject matter experts and HIV program staff with experience and knowledge in these areas to present during one of the four topic-specific webinars. This resource document is a summary of the webinars; it provides strategies and tools for health departments to continue to improve integration and collaboration among surveillance and prevention programs.¹

DATA TO CARE

Data to care (D2C) is defined as the use of HIV surveillance data to identify people living with HIV (PLWH) who are out-of-care and/or not virally suppressed and re-engage them in care.

Examining the Evidence

(Based on presentation by Julie Dombrowski, MD MPH, Seattle-King County Public Health)

A review of health department studies on various aspects of D2C identified four key points:

- 1. Most people who appear to be out of care based on surveillance data are not actually out of care.[1-6] In these studies, 47-72% of people classified as 'out of care' by HIV surveillance have an alternate explanation. The most common explanations are that they are actually in care but didn't get lab testing, they are deceased, they've moved out of the area, or that labs are not being reported to surveillance.
- 2. In most cases, D2C efforts based only on HIV surveillance data are not an efficient way of re-linking people to care.[3, 7-10] Among health departments that have examined this, only 3-15% of people identified as being out of care and not having died or moved were successfully contacted and re-engaged in care.
- 3. Many who are out of care and do re-engage in care would probably have re-engaged with care independent of D2C efforts.[7] [Louisiana Dept. of Health unpublished data presented in webinar]
- 4. For those who are re-linked to care, the success may be only for a short time and not an ongoing care relationship.[11]

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D2C in Seattle-King County, Washington

(Based on presentation by Julie Dombrowski, MD MPH, Seattle-King County Public Health)

The Seattle-King County, Washington health department designed a collaborative prevention-surveillance program to address the above limitations. The program has two key components:

- Facility-based D2C using real time data exchange: Through data-sharing agreements with Seattle hospitals and the local jail, out-of-care patients are identified as they arrive at an emergency department, are admitted to inpatient services, or are booked into jail. An alert is then sent to the re-linkage team (1.5 dedicated DIS) which follows up while the patient is in the emergency department or hospital, or with jail-release planners during weekly case-conferences.
- The Max Clinic [12] provides comprehensive care for high-needs patients including those with unstable housing, substance use disorders, and/or untreated mental health disorders. The clinic offers many services, but found the following to be most impactful:
 - » Low-threshold to care: Patients have walk-in access to medical care five afternoons/week and full-time access to case managers. Case managers are available directly by phone and text, so patients don't have to use a phone tree.
 - » Incentives: Patients receive snacks at each visit, meal vouchers once a week, unrestricted bus passes, and cash incentives for visits and suppressed viral load.
 - » High intensity outreach and support: Non-medical and medical case managers, and DIS (2.0 dedicated to the clinic, including D2C activities for Max patients) provide outreach and support using a harm reduction approach; clients perceive these individuals as caring, supportive, and non-judgmental. Evaluation data suggest that case managers have more impact than medical providers.

D2C in Louisiana

(Based on presentation by Jacky Bickham, MPA and Debbie Wendell, PhD MPH, Louisiana Dept. of Health)

- Louisiana started D2C in 2013. Using surveillance data, patients are added automatically to weekly not-in-care lists which are managed in an Access-based case management system developed in-house. The system serves as the single master database for D2C and has a variety of case management, search, alert, and quality control functions.
- Linkage-to-care coordinators (LCC) are state staff dedicated to D2C work. Nine LCCs work statewide and conduct the initial research to locate a client and subsequent client contact. LCCs have smaller caseloads than DIS and more time to focus on individuals.
- LCCs use eHARS, STI surveillance data, Medicaid data, Accurint, and CAREWare to find current contact info
 for patients. LCCs complete case report forms with new information to update eHARS which has increased
 surveillance data quality.
- LCCs address social service needs and help clients fill out applications, find employment, and get enrolled in GED programs. They connect patients to medical providers that patients are comfortable with and attend at least the first two medical appointments with the patient, keeping the patient on their caseload until they are virally suppressed.

Summary of D2C

• D2C is effective at improving the quality of surveillance data and has some impact on re-linking PLWH who are out of care to one care appointment. However, it does not seem to have a sustained impact on long-term engagement in care or viral suppression.

- To date, effectiveness has been limited by inaccuracies in surveillance data, difficulty finding out-of-care individuals, and lack of effective interventions to re-engage people.
- Improvements in surveillance data and real-time D2C approaches (surveillance data supplemented with real-time data sources) are promising ways of increasing D2C effectiveness but improving care for the hardest-to-reach PLWH is also needed.
- Prevention and surveillance programs can collaborate on important evaluation and implementation questions such as determining how to effectively identify people who are out of care and need support to re-engage, selecting the best data sources for accurate out-of-care lists, examining prioritization algorithms to support staff efficiency, determining how to identify people who are likely to fall out of care before they actually do so, and re-designing care systems to best support people with significant barriers.

Resources

- » In addition to the Seattle Max clinic, other clinics tailored to provide care to high needs patients are H-PACT (VA program for people experiencing homelessness that provides wrap-around social and medical services to high-need patients[13]) and the Vancouver Maximally Assisted Therapy (MAT) program for high-needs PLWH (https://www.catie.ca/en/pc/program/mat-program). A MAT-like program for indigenous PLWH in Vancouver ran until 2018 when it lost funding.
- » See reference list for specific articles.

EFFECTIVELY USING DATA TO SUPPORT PROGRAMS

HIV Data Privacy and Confidentiality

(Based on presentation by Amy Killelea, JD, NASTAD)

NASTAD reviewed laws/statutes², regulations³, policies⁴, and practices⁵ related to HIV data release by health departments in 20 states. The findings are summarized here⁶.

- HIV confidentiality laws generally prohibit releasing identifiable HIV data except to 1) carry out public health functions, 2) respond to public health emergencies, 3) conduct statistical and research activities, 4) enforce control measures, and 5) respond to a court order or subpoena.
- Most laws/regulations don't address new activities like D2C, sharing data with Medicaid, or molecular HIV surveillance (MHS). However, most health departments have broad discretion around deciding if or how to do these types of activities.
- Data to care: Data sharing among HIV programs (within and between states) for D2C is almost always allowed without a formal data sharing agreement. Most states choose to further limit data sharing in a variety of ways.
- Medicaid: In all states examined, data sharing with Medicaid requires formal data-sharing agreements. There are often state-specific limits on what can be shared.

² The terms "statute" and "law" refer to the same things.

³ Regulations are formal legal directives on how to implement laws. They carry almost as much weight as laws.

⁴ Policies are written guidance on how things are supposed to work routinely, such as standard operating procedures or published interpretations of laws or regulations. They carry less weight than regulations.

⁵ Practices are routine activities related to applying laws/regulations/policies but are not written or formalized.

⁶ Note that not all states were included, and laws, regulations, and policies vary substantially between states.

• Law enforcement: There are multiple factors that vary between states impacting whether health departments are compelled to release data to law enforcement: 1) how data is requested (e.g., court order); 2) what types of data can be released; 3) when data can be requested; and 4) what protections the data have after release.

Georgetown HIV Data Sharing Projects

(Based on presentation by Auntré Hamp, MEd, MPH, Health Data Analytics program at Georgetown University)

The Health Data Analytics program at Georgetown University supports a variety of projects geared toward improving the use of surveillance data for prevention and care activities:

- The ATra Black Box system [14] provides a secure way to share datasets among health departments. Since
 the system uses identifiers (unlike CDC's Soundex check), it helps de-duplicate case records, update care
 status to support D2C, and improve surveillance data quality. There are currently 26 jurisdictions actively
 participating in the Black Box.
- Georgetown has supported efforts to link STI and HIV data to identify candidates for PrEP, persons who need STI treatment, and persons with repeat STI infections and provided technical assistance to support linking STI, HIV, and Ryan White data.
- If you want to participate in the Black Box project or ask for help with other data linking/sharing projects, email Georgetown at: <u>ps18_1805@georgetown.edu</u>.

California Data Integration Activities to Support STD/HIV Field Investigations

(Based on presentation by Ryan Murphy, PhD MPH and Will Wheeler, PhD MPH, California Dept. of Public Health)

HIV and STI programs in many California local health departments are separate and do not coordinate on field investigations. Until recently, they had limited access to HIV surveillance data and used different systems to access HIV and STI prevention and surveillance data. Surveillance and prevention staff in the state HIV and STD programs collaborated to develop IT solutions that would support local collaboration in HIV and STI surveillance and prevention activities. They conducted multiple, detailed consultations with local front-line staff to fully understand their needs and workflow, and subsequently implemented two new projects.

- STD/HIV Field Investigation Incident (SHFII) was developed in CalREDIE, a web-based surveillance system.
 SHFII is designed to facilitate HIV/STD case investigations by organizing information in a way that is
 consistent with workflows. It includes information on the original patient and contacts/partners, investigation
 status, and linkage to care and services for HIV, HCV, STD, and PrEP. Using SHFII eliminates the need
 for duplicate data entry into multiple systems and supports follow-up records to track surveillance and
 prevention workflows.
- Local Interventional Surveillance Access (LISA) provides access to data and tools that are not available through CalREDIE, such as historical HIV and STI data, line lists, data-to-care lists, summary reports, and individual-, team-, and agency-level performance measures including HIV care continuum metrics. LISA is an R-Studio-based system developed by state staff that pulls from CalREDIE, eHARS, Ryan White data, electronic lab reporting data, and SecureTrace (for MHS) on a nightly basis. People newly identified as needing follow-up (e.g., newly diagnosed, newly out of care, newly part of a cluster) are flagged in LISA. Cases with completed follow-up have data uploaded to eHARS. The integrated data system enables prevention and surveillance staff to more effectively collaborate on program implementation at multiple levels.

Summary of Effectively Using Data to Support Programs

- HIV surveillance and prevention programs should collaborate with their in-house legal counsel to review
 relevant statutes and regulations around sharing and releasing HIV data. Health departments have
 substantial discretion around interpreting and applying laws and regulations. Legal counsel input is essential
 to ensure that these are applied in as protective a way as possible while also balancing the needs of the
 health department.
- The Georgetown University Black Box project improves surveillance data quality which supports many
 programmatic prevention and care activities. Georgetown also supports other data linking projects that
 impact prevention and care outcomes.
- There are multiple approaches to integrating HIV and STD surveillance and prevention data to support
 program activities (see other topic summaries for additional examples). Many can be implemented using
 in-house resources and can improve staff efficiency around case investigations, patient outreach, and overall
 program implementation. Any project should involve substantial consultation with staff doing front-line
 work.

Resources

- » Additional resources on HIV data privacy and confidentiality are the NASTAD brief on HIV Data Privacy and Confidentiality (https://www.nastad.org/sites/default/files/Uploads/2018/nastad-hiv-data-privacy-06062018.pdf), the NASTAD website on Health Systems Integration Data Sharing Resources (https://www.nastad.org/domestic/health-systems-data), and a journal article on HIV criminalization laws and legal protections for surveillance data.[15]
- » See reference list for specific articles.

HIV CLUSTERS

The definition of a 'cluster' varies. It can refer to a higher than expected incidence of disease in a specific time or space, or to a group of people with a disease who are connected in some way. 'Cluster,' 'outbreak,' and 'epidemic' are defined similarly. CDC defines an 'HIV transmission cluster' as a group of HIV infected persons who are connected by HIV transmission.

Michigan's Integration of HIV Surveillance and Prevention Programs

(Based on presentation by Mary-Grace Brandt, PhD, MPH, Michigan Dept. of Health and Human Services)

Prior to 2019, the Michigan HIV surveillance program was organizationally separate from HIV and STD program activities. PS18-1802 was an opportunity to re-evaluate how surveillance and prevention work together. The health department worked with the Michigan Public Health Institute (MPHI) (https://www.mphi.org) to map HIV surveillance and prevention business processes, and conduct programmatic needs assessments and gap analyses. A written summary of existing workflows, challenges and barriers, and programmatic goals/objectives became the basis of a re-visioning and re-organization process. HIV surveillance was organizationally integrated with HIV prevention and two cross-cutting activities were implemented.

- Hiring a project facilitator: MPHI hired a project management/quality improvement expert to support the revisioning/re-organization. She led efforts to develop and document new work processes, build staff support for changes, facilitate projects, increase communication, connect staff with resources, identify areas that would benefit from process improvement, and ensure deliverables were met.
- IT infrastructure: The prevention and surveillance data systems were integrated and a SharePoint-based system was implemented to support HIV-STD work coordination. The system is a one-stop shop for

announcements, calendars, forms, program resources, management updates, resource manuals, and data dictionaries used by both programs.

The changes have significantly improved coordination and collaboration among the HIV prevention and surveillance programs, and between the HIV and STI programs.

Michigan's Cluster Detection and Response Program

A new cluster detection and response process [the Shared HIV Networks (SHiNe) program] was also developed. The health department did substantial outreach to solicit community involvement in re-visioning MHS. The resulting focus groups helped develop goals, a new program name, protocols, scripts for talking to community members, and redesigned terminology to make it more community-friendly. These products informed the development of health department protocols which were then shared with the focus groups for feedback.

- Three experienced DIS were dedicated to work with SHiNe after receiving additional training on MHS and how to communicate with communities about it.
- Michigan has used SHiNe to respond to two HIV clusters to date. When compared to previous cluster
 responses, SHiNe responses had more buy-in and support from local health departments, DIS were more
 successful in eliciting partners, and communities were more willing to commit additional testing resources to
 the responses.

HIV Cluster Detection and Response Planning

(Based on presentation by Juliana Grant, MD, MPH, Public Health Nerds, LLC)

CDC requires funded health departments have an HIV cluster detection and response plan. Cluster detection and response planning also helps develop coordinated and targeted activities for those at highest risk of acquiring HIV and those having trouble achieving viral suppression, efforts needed to end the epidemic. Ideally, a cluster detection and response plan outlines specific health department staff and partner activities during cluster detection and response.

A first step in developing a useful cluster detection and response plan is determining who should be on the planning group. While local health departments, community members, and many other external partners should have input on the plan, a smaller group is best for developing the initial draft. This planning group should include representatives from 1) HIV surveillance/data management/epidemiology, 2) HIV prevention/partner services/DIS, 3) Ryan White/HIV care and treatment, and 4) STI and/or hepatitis. It may also be appropriate to include local health departments, homeless services, harm reduction/Injection drug use services, corrections, public health laboratories, and health department executive leadership. At a minimum, cluster detection and response planning should be jointly conducted by HIV surveillance and prevention programs.

Only 31% of webinar participants were very confident that their health department had the people they needed for a planning group. If needed expertise isn't available in your health department, there are other sources of support: CDC, CSTE, other programs in the health department (e.g., STD, hepatitis, or tuberculosis), other health departments, CDC-funded capacity-building assistance providers, community-based organizations or AIDS-services organizations that provide prevention, care, homeless, harm reduction, or syringe-exchange services, healthcare providers, community organizations, HIV advocacy groups, state and local HIV planning groups, consumer advisory groups, HOPWA providers, the Harm Reduction Coalition, correctional healthcare providers, and the state prison system.

Summary of HIV Clusters

- Prevention-surveillance collaboration is an essential part of HIV cluster detection and response planning
 and responses. While conducting detailed workflow analyses and developing written protocols and
 documentation for collaborative activities is a substantial time investment, it is a worthwhile effort that pays
 off in the long run.
- Proactively involving impacted communities in cluster detection and response planning leads to stronger relationships with these communities and more effective cluster detection and response.
- For health departments that don't have key resources to support cluster detection and response planning, including outside partners in the process can be a useful source of expertise.
- Resources
 - » CDC PS18-1802 Attachment E: Detecting and responding to HIV transmission clusters: a guide for health departments: https://www.cdc.gov/hiv/pdf/funding/announcements/ps18-1802/CDC-HIV-PS18-1802-AttachmentE-Detecting-Investigating-and-Responding-to-HIV-Transmission-Clusters.pdf
 - » CDC-funded Capacity-building assistance provider network: https://www.cdc.gov/hiv/pdf/capacity-building-assistance-directory.pdf
 - » Harm Reduction Coalition: https://harmreduction.org
 - » To request documents describing the Michigan SHiNe program, email Jacob Watson (<u>WatsonJ11@michigan.gov</u>).

THE EXPANDING ROLE OF DIS

Implementing D2C, MHS, and routine partner services has dramatically increased DIS workload in many areas. Two health departments shared their experience with improving prevention-surveillance collaboration to address these changes.

Massachusetts

(Based on presentation by Kathleen Roosevelt, Massachusetts Dept. of Public Health)

The Massachusetts Office of HIV/AIDS oversees contracted providers for HIV testing, linkage-to-care, and care services. HIV surveillance and DIS activities are in the Division of STD Prevention. D2C and routine follow-up on acute HIV cases has been in place since 2015. In 2016, a cluster of new HIV infections in people who inject drugs was identified. Based on these experiences, the health department recognized that effective field-based contact with patients could have substantial impact on the epidemic. However, integrating this into routine work required several changes to improve collaboration among surveillance, prevention, and care activities:

- Expanding the DIS team and changing job requirements: The number of DIS was increased from 8 to 18 using state, CDC and Ryan White funds. The job classification was changed to "Field Epidemiologist" to reflect the expanded workload and a deeper understanding of the DIS role in HIV surveillance (e.g., interpreting and presenting data analyses). The new classification enabled higher starting salaries which supported hiring and retaining more qualified and more diverse staff, including bicultural/bilingual DIS.
- Integrating surveillance and case management systems: Previously HIV surveillance data were only available in eHARS and DIS didn't have access to the system. HIV data were migrated into MAVEN (a web-based surveillance and case management system) in 2018. This dramatically improved Field Epidemiologist access to information on new cases and streamlined workflows, which made them more effective in conducting partner services and prevention activities. Field Epidemiologists could also help complete case report forms which increased surveillance epidemiologist ability to do analytic projects.

 Provider buy-in around routine partner services: The health department started doing routine partner services for all people newly diagnosed with HIV in early 2019. To address provider concerns about this, the health department met with the highest volume HIV providers and embedded Field Epidemiologists in those clinics which improve coordination between prevention and care providers.

As a result of these changes, Field Epidemiologists now conduct routine partner services for all PLWH, including connecting HIV-negative partners to PrEP, work with testing partners to help ensure linkage to care for newly diagnosed PLWH, work with care providers to support reengagement in care, and interview patients to obtain complete and accurate information for surveillance on risk behaviors, current address, incarceration status, gender, and race/ethnicity.

Vermont

(Based on presentation by Daniel Daltry, Vermont Dept. of Health)

The Vermont Dept. of Health has an integrated program - HIV surveillance and HIV prevention are both located in the HIV/STD/Hepatitis Program. Prior to PS18-1802, the program could only support 0.5 DIS and the field activities were conducted by the program coordinator. With PS18-1802, support for DIS increased and they were able to hire a full-time DIS.

DIS roles/responsibilities in Vermont include:

- Patient interviews
- Completing case report forms
- Patient education
- Partner services
- Investigating risk networks
- Linkage and reengagement to care
- Adherence counseling
- Patient navigation for insurance coverage and housing
- Identifying HIV clusters/outbreaks

Currently, DIS follow up with all of the following types of individuals:

- All persons newly diagnosed with HIV: The DIS collaborate with testing and medical providers to be onsite with patients when confirmatory testing is done.
- People with test results indicative of acute HIV
- People living with HIV with
 - » CD4 counts <200 cell/µL
 - » Unsuppressed viral load
- MSM diagnosed with rectal gonorrhea/chlamydia or infectious syphilis (to offer PrEP).
- People with acute Hepatitis C (to assess need for HAV/HBV vaccination and PrEP)
- Any new applicants to the Medication Assistance Program
- Anyone in danger of losing access to the Medication Assistance Program

DIS collaborate closely with HIV surveillance and other partners (e.g., medical providers) to coordinate patient outreach, linkage and reengagement in care, and cluster responses.

Summary of the Expanding Role of DIS

- DIS activities are essential for implementing D2C, MHS, and partner services. They also build effective partnerships with providers. Strong collaboration between surveillance, prevention, and care is needed for DIS to effectively conduct these activities.
- Consistent access to timely surveillance data is essential for DIS to do effective field work. DIS work interviewing patients also leads to improved timeliness, accuracy, and completeness of surveillance data.
- Resources
 - » CDC-funded Capacity-building assistance provider network: https://www.cdc.gov/hiv/pdf/capacity-building-assistance-directory.pdf
 - » CDC's website on STD prevention courses (including the Passport to Partner Services training): https://www.cdc.gov/std/training/courses.htm
 - » Massachusetts Field Epidemiologist position description: https://mapublichealth.org/2018/02/09/job-posting-for-mass-department-of-public-health-field-epidemiologist/

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