Describing Health Department Programs Using HIV Surveillance Data for Linkage/Re-Engagement to Care Activities

The following program description was written by representatives from the Washington State Department of Health (DOH), the Office of Infectious Disease (OID). The description is provided as an example of how this jurisdiction is conducting Data to Care work. CDC has not been involved in the development, implementation or evaluation of this program.

Project Overview

Washington State has adopted a statewide "treatment as prevention" model which focuses on ensuring that all people living with HIV are diagnosed, linked to consistent, optimal HIV medical care, receive antiretroviral treatment, and have a suppressed viral load. To this end, all HIV-positive individuals are considered the top priority from both a HIV prevention and care perspective.

Within the Washington State Department of Health (DOH), the Office of Infectious Disease (OID) coordinates and oversees several Data to Care activities that support the HIV Continuum of Care. Primary activities include using surveillance data to identify, locate, and offer care linkage/re-engagement services to persons living with HIV who are either not receiving medical care, or who receive care but have not achieved viral suppression.

In partnership with local health departments, OID has become increasingly integrated across sections and programs to ensure that all people living with HIV disease (PLWH) are diagnosed, linked to HIV medical care, receive optimal medical treatment, and are retained in ongoing medical treatment.

The Seattle metropolitan area is the largest in Washington and is where the majority of all persons living with HIV reside. As such, the Public Health-Seattle & King County (PHSKC) HIV/STD Program works in close collaboration with DOH to conduct local HIV surveillance and prevention activities.

Program Integration

HIV/STD surveillance, HIV/STD prevention services, and HIV care services are consolidated within OID. The Infectious Disease Prevention Section (IDPS) collaborates closely with both the Infectious Disease Assessment Unit (where the HIV and STD surveillance programs are located) as well as with the HIV Client Services program (location of the state's AIDS Drug Assistance Program). OID staff members collaborate closely across program areas to support a comprehensive set of services that address needs at every point along the HIV continuum of care, from initial diagnosis to treatment initiation and viral suppression.

DIVISION OF DISEASE CONTROL AND HEALTH STATISTICS
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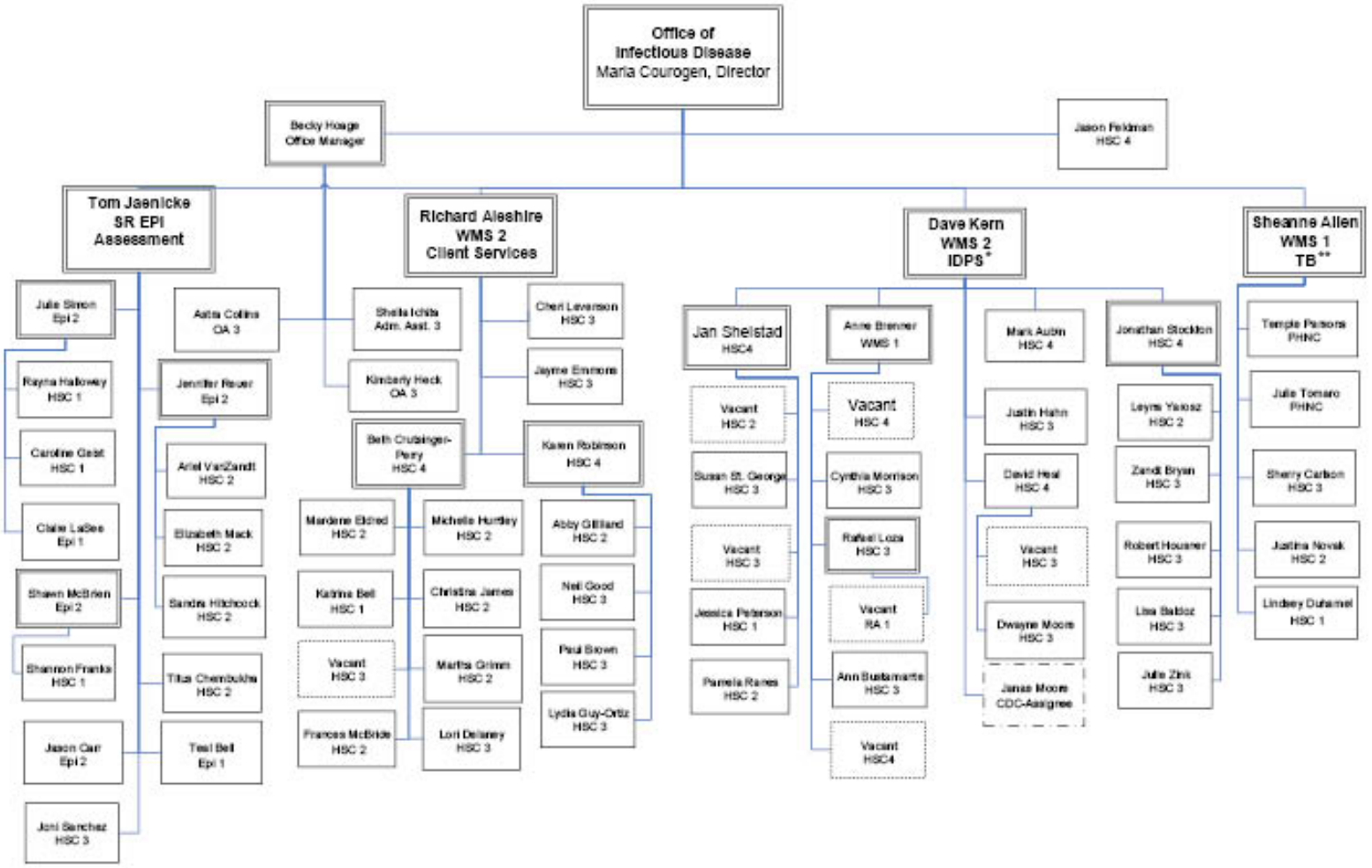


* Infectious Disease Prevention Section
** Tuberculosis Section

Revisions to STD and HIV disease investigation protocols have been made to ensure improved surveillance and access to medical care for co-infected persons. This integrated approach includes financial and staff resource sharing across formerly independently operating units in the OID. As teams develop solutions to problems posed at each stage of the HIV cascade, information and program resources are structured to ensure that these elements work together as part of a comprehensive system geared to achieve specific outcomes. The intersections and interactions of OID supported programs are being mapped and analyzed to identify future synergies, and new business procedures are being developed to promote increased collaboration and accountability for cross-sectional projects and programs.

Organizational development to achieve program integration has been underway in the OID at DOH for several years. In 2011, focused study and dialogue within DOH led to the realization that funding and administration divisions among HIV programs could inhibit state and local efforts to align with the National HIV/AIDS Strategy (NHAS). Gaps in service and data capacity, as well as areas for development, were identified as a result of this process. This process has since accelerated with infrastructure alignments, resource sharing, and cross sectional team building having priority.

Similarly, realignment of community programs to focus resources on areas of the state with the greatest burden of HIV disease, while ensuring minimum service levels throughout the state, began in 2011. Further realignment of community programs to function in partnership with DOH in an outcome-driven, comprehensive service system that includes HIV prevention and care services began in July 2013. This work is in keeping with a new strategic model, which envisions reducing new HIV infections in Washington by 50% within a five-year period.

To achieve better programmatic collaboration, the OID has been reorganized to facilitate communication and collaboration between sections and increase efficiency. OID is in the process of adopting office-wide goals and has formed cross sectional teams to carry out projects that integrate formerly separate business areas within the office. These teams can operate semi-autonomously to organize their work and define expected results, using iterative processes to solve problems and achieve outcomes. This reduces bureaucratic drag and supports innovation, while building the links and ongoing relationships across the office that are needed for further integration.

A Brief History of Re-Engagement in Washington State

Between 2010 and 2011, DOH and PHSKC supported a pilot program in King County called NOTICE. The purpose of NOTICE was to promote HIV care linkage/engagement and use of ART among PLWH by using surveillance data to identify persons diagnosed with HIV for ≥6 months with a CD4 count ≤500 cells/mm^3 and VL ≥500 copies/mL at the time of last report. Persons determined through investigation to have died, moved away or be receiving care at a clinic not covered by the pilot were excluded from the project. Eligible PLWH were offered an individual intervention designed to identify and address barriers to HIV care and ART use in coordination with medical and social service providers. Program acceptability, uptake, and participant-reported barriers to care and ART use were analyzed. Of 260 eligible cases identified, DIS successfully contacted 113 (43%). Eighty-nine (89) accepted referral to a linkage/re-engagement program (79% of contacted; 34% of eligible), and 75 completed the individual intervention (84% of accepted; 29% of eligible). Based on the results of this initial study, DOH and PHSKC jointly began a project to extend the project statewide. What started as NOTICE is now becoming the state's new Locating Out-of-Care (LOOC) data system

Data to Care Activities in Washington

DOH uses a **Combination Health Department/Healthcare Provider Model** to conduct Data to Care activities in Washington. This involves working through a network of private providers, community based organizations (CBOs), and/or local (county) health jurisdictions to reach clients. At the county-level, Disease Intervention Specialists (DIS) help recently diagnosed cases get linked to optimal medical care. They also work with the state and local surveillance programs to re-engage clients who have either fallen out of care or were never linked to care following diagnosis. In addition, DOH employs a small group of Infectious Disease Prevention Specialists who can contact healthcare providers or establish direct contact with clients in order to deliver HIV/STD partner services and linkage/re-engagement services. These Prevention Specialists can also provide technical assistance to local health jurisdictions upon request, and help support local jurisdictions that are otherwise too small to employ their own DIS.

On a quarterly basis, a surveillance epidemiologist queries the state's HIV surveillance system (eHARS) for prevalent HIV cases that do not appear to be receiving optimal HIV medical care, or care that leads to the suppression of viral load. Case selection is primarily based on available lab data contained in the state's comprehensive, electronic laboratory reporting system. The sample includes individuals who have and have not been linked to care in the past, but is restricted to those who appear to be current Washington residents diagnosed more than 12 months prior to the date of inquiry. Baseline information about these cases is then uploaded to the LOOC data system. LOOC is a custom-built, web-based data system that debuted in 2013. The system is used to investigate and document the whereabouts and HIV care status of potentially out-of-care cases. LOOC uses applications developed by the IT firm DatStat, Inc., which is based in Seattle. Most information associated with initial linkage to care, re-investigation, and/or care re-engagement is being entered and stored electronically in the LOOC database. However, in some cases, such as when a DIS is conducting medical chart abstractions in the field, some data is temporarily collected on paper until electronic data entry is possible.

LOOC data serve as the foundation for subsequent investigations and linkage/re-engagement activities. Via a feedback loop, these data help improve the quality and completeness of surveillance data, and are being used to identify provider and/or laboratory reporting gaps. Out-of-care cases that are eligible and willing can be referred (electronically, from within the LOOC system) to appropriate interventions such the Care and ART Promotion Program (CAPP), which is similar to ARTAS but focuses more on care re-engagement vs. initial linkage. More information about both LOOC and CAPP is available in the next section.

LOOC Work Flow

Step 1. On a quarterly basis, an HIV surveillance epidemiologist checks the HIV surveillance database (eHARS) for prevalent HIV cases diagnosed at least 12 months prior who fall into one of the following two categories:

No Labs – no CD4 or viral load result reported to surveillance within past 12 months (from date of inquiry).

Marginal Labs – Both CD4 and viral load lab results reported within past 12 months. However, last viral load result > 500 copies/mL and last CD4 result < 500 cells/µL.

Step 2. A surveillance epidemiologist prepares an individual-level line listing of cases that fall into one of the two categories above for import into LOOC system. These data contain the client's name, best

available contact information (as entered in eHARS), provider information, lab data, as well as additional identifying information which is necessary to support further investigation and linkage/re-engagement activities.

Step 3. An internal investigation is performed to supplement case surveillance data stored in LOOC system by checking other data systems such as LexisNexis Accurint, the state's STD disease registry, the state's ADAP registry, and the state's CareWare data system. Information is considered current if reported or collected from a client within the past two years. DOH-employed DIS work closely with case surveillance staff to verify out-of-state residence or deceased vital status, and such cases are not investigated further. DIS conducting internal investigations generally don't make direct contact with providers or patients. Once current whereabouts and HIV care status are obtained, or once all data resources have been exhausted in searching for locating information, client investigations are handed over (within the LOOC system) to DIS at the local level for external investigation. Local assignment is based on last known county of provider (if current), or last known county of residence if last known provider data aren't available.

Step 4. An external investigation is then performed by either local DIS working within local health jurisdictions (LHJs) or, in some cases, by Infectious Disease Prevention Specialists who are responsible for parts of the state where local DIS capacity is low. DIS conducting external investigations leverage local data resources to enter new data or verify existing data in LOOC. Examples of local data resources are remote access to electronic medical record systems, jail rosters, and social networking sites. When necessary, local DIS can also make direct contact with providers or patients. Locating information is considered "verified" if confirmed by patient's current provider, an electronic medical record, or if the information led to successful contact with the patient. Excluding cases with marginal labs, an individual is considered to be "in care" if he/she had a documented medical appointment with an HIV provider within the past six months, or an appointment scheduled within the next two months. An "appointment" is defined as a medical visit that results in at least one of the following: a CD4 laboratory result, a viral load result, or the provision of an HIV-related prescription for medication. However, to simplify the task of assessing HIV care status in the field, DIS often check to see whether a patient has had a documented, provider-verified visit within the past six months, and whether the same patient has an appointment scheduled within the next two months.

The main goal of LOOC investigations is to locate and assist those in need of optimal HIV medical care. Local DIS can attempt to re-link cases to care using their own skills and resources, or they can refer cases to CAPP, an individual-level, behavioral intervention developed by researchers at Public Health-Seattle & King County and the University of Washington. The intervention is based on the Information-Motivation-Behavioral Skills Model and the Behavioral Model for Vulnerable Populations. CAPP assumes that increasing a participant's information and motivation can help develop behavioral skills needed to engage with case management, social support services, and HIV medical care including ARV treatment. Those who consent to CAPP will be contacted by a CAPP specialist and undergo a structured motivational interview which is intended to identify barriers to care and how to overcome them. The interview can be completed either in person or by phone, with a follow-up call scheduled approximately four weeks later. CAPP includes a one-on-one meeting with a counselor to discuss barriers to care and ART use and to develop plans to surmount them. Participants attending face-to-face CAPP meetings receive a $50 grocery voucher. Where appropriate, the CAPP specialist can provide the participant with direct assistance in getting

linked/re-engaged to HIV medical care. The LOOC and CAPP data system are connected in a manner that allows cases to be referred electronically from one to the other.

Step 5. During the course of LOOC investigations, it is common to locate information previously unreported to the case surveillance system. These data may potentially improve the quality of surveillance data stored in eHARS and become the baseline for future linkage/re-engagement activities (if needed). Therefore, case surveillance staff members are given the opportunity to review new data collected in LOOC and import verified data into eHARS when deemed appropriate.

Data

Washington has had a statewide, electronic laboratory surveillance system for AIDS-related laboratory results in place since late 1999, and a comprehensive HIV/AIDS laboratory reporting system (capturing all HIV confirmatory tests, as well as all viral load and CD4 results) since 2006. State law requires that all HIV-related laboratory results are reported to the appropriate state or local health department in a timely manner. The majority of HIV lab data are reported electronically to the state health department via a central data portal and clearinghouse called the Public Health Reporting of Electronic Data (PHRED) system. Surveillance staff members use a custom-built data application called LabTracker to extract HIV-related lab results from PHRED. Staff members then regularly match LabTracker data with eHARS data to determine which results need to be imported into eHARS, and to trigger new case investigations. Lab data are consistently monitored for completeness by provider, health facility, county and/or local health jurisdiction. When necessary, staff members work with labs and providers to understand why reported data are incomplete, and to address and resolve reporting barriers. The surveillance program also publishes stratified CD4 and viral load data in semi-annual, statewide surveillance reports and in other data products. Washington typically exceeds all CDC outcome standards related to the completeness and timeliness of lab reporting.

As mentioned above, state and local DIS use a variety of data resources to supplement case surveillance data pulled from eHARS and to inform linkage/re-engagement efforts. These data resources include LexisNexis Accurint, an ancillary laboratory surveillance data system called LabTracker, the state's STD and HIV/STD Partner Services registry (PHIMS STD), the state's ADAP data system (HADS), state Department of Licensing data, state Department of Corrections data, as well as remote access to hospital-based electronic medical records systems. For the time being, review of these data systems is done manually. However, as familiarity with each system improves, including its relative contribution towards the improvement of surveillance data quality and the delivery of linkage/re-engagement services, DOH is working towards developing the capacity to improve the efficiency of out-of-care investigations and to automate the process of gathering useful information where available.

In addition to using surveillance data to trigger LOOC investigations, DOH also has the capacity to conduct potentially more timely investigations with clients participating in the state's ADAP and medical case management programs. For example, evidence that a client has not filled an HIV prescription leads to efforts by HIV Client Services to contact the client and attempt to re-engage him in medical care, if necessary, typically with the support of a Ryan White medical case manager. For a small number of cases at each quarterly review, attempts to contact clients are unsuccessful for a variety of possible reasons. These include clients who have moved out-of-state, are deceased, or have changed telephone numbers or addresses without notifying ADAP or another Ryan White service provider. These cases are referred to the LOOC system for investigation and contact by linkage/re-engagement specialists at the

local health jurisdiction level. If new or more accurate information is obtained, contact attempts are made by the client's medical case manager (if applicable), or a linkage/re-engagement specialist to offer the client assistance to link/re-engage with medical treatment.

DOH is in the process of developing a statewide CareWare database to which all Ryan White service providers will have remote, patient-level access. Once all service providers are linked, criteria will be identified that allow this system to identify clients who are most at risk of treatment interruptions and to direct more intensive services to them. Services might include ARTAS, treatment adherence support, or other social support services needed to allow re-entry into care.

Patients' personal identifiers have always been and continue to be handled with a great deal of care. Traditionally, access to protected health information (PHI) such as name, date of birth, and locating information have been heavily restricted to only a small number of state and local HIV surveillance staff members and DIS who are affiliated with a patient's county of residence at HIV or AIDS diagnosis. For the most part, those were the only individuals who could claim a public health need to access these data, as state law requires. However, we have recently begun to re-evaluate some of our conventional attitudes towards data sharing, as well as assumptions regarding what we are allowed to share, with whom, and under what circumstances. In Washington, state law allows confidential data to be shared with certain public health partners, as long as the data are handled securely and the sharing of such data is in direct support of public health services. Although the decision to share data is still made on a case by case basis, we now realize that in some cases it is necessary to share these kinds of data with public health partners such as medical case managers, care linkage/re-engagement specialists within local CBOs, and so on. We have also begun sharing these data with DIS who don't work in the jurisdiction where a case lives, but do work where that case appears to be receiving (or has received) HIV medical care. OID is currently updating data confidentiality and security policies to reflect the broader degree of data sharing that is occurring.

Key operational features of program

Much of the linkage/re-engagement work described here is new to DOH. These systems and processes have been developed as part of Washington's CDC 12-1201 Cooperative Agreement: Category C Demonstration project. A primary purpose of this project is to determine the nature and volume of resources necessary to deliver linkage/re-engagement services statewide. DOH has made clear that it is committed to working closely with project partners to monitor and address local resource needs. As the project moves forward, and project-related data become available, we will be in a better position to predict the costs of maintaining these systems over time. However, it must be recognized that the investments being made--to create new systems, to establish new and/or expanded roles, and to work through a sizeable backlog of cases (>3,500 statewide) potentially in need of linkage/re-engagement services--are unique to the project timeframe and are substantially greater than they will be once these systems have been built and the backlog no longer exists.

The following represents current estimates of internal/external staffing needs to complete surveillance-supported linkage/re-engagement efforts; these estimates are resource-dependent and subject to change as programs evolve and our understanding of population needs improves.

Internal FTEs: 2.5

- In-house disease investigator (0.5 @ 100%)
- Category C project coordinator (0.5 @ 100%)

- Linkage and retention in care coordinator (0.25 @ 100%)
- Linkage and retention in care lead (0.25 @ 100%)
- Infectious Disease Prevention Specialists (4 @ 12.5%)
- Epidemiologist (0.5 @ 50%, 1 @ 25%)

External FTEs: 2.5

- External DIS (8 @ 12.5%),
- CAPP specialists (10 @ 10%Administrative support (0.5 @ 100%)

During the initial year of its current CDC Cooperative Agreement for HIV Prevention, IDPS prioritized linkage to medical care for newly diagnosed PLWH and began implementing a system that assigns responsibility for verifying linkage to care to HIV testing providers (publicly funded sites) or to HIV partner services staff (private sector diagnoses). ARTAS training was provided to an initial group of HIV testing staff, partner services DIS, and HIV case managers from selected areas of Washington. The initial session of ARTAS is now integrated with post-test counseling for persons newly diagnosed in non-clinical settings. The principles of ARTAS are also incorporated into HIV partner services to assist PLWH to overcome barriers that may interfere with their access to optimal medical care and treatment with ARVs.

Both linkage to care and care re-engagement services are available to all people living with HIV in Washington, regardless of where they live. All PLWH are also monitored using eHARS and laboratory data to determine whether they are receiving medical treatment and if that treatment appears to meet DOH-established standards of care. Cases identified as being potentially out-of-care are investigated to determine the actual circumstances. Clients who are out-of-care and can be located are contacted and offered assistance to link/re-engage with medical treatment. This assistance can take several forms including referral to a medical provider, a case management provider, an ARTAS provider, or a CAPP specialist. While ARTAS and Ryan White medical case management are available to clients throughout the state, CAPP implementation is focused on the three areas of Washington with the highest HIV prevalence.

The Category C Demonstration project will provide crucial data necessary to better estimate the amount of funding necessary to deliver surveillance-supported linkage/retention/re-engagement services statewide. However, the costs of working through the current backlog of potentially out-of-care cases are unique to the project time period. Once the backlog is cleared, costs will likely be much lower. Nevertheless, these new systems are not cheap and will require a substantial commitment of resources from DOH over the next several years. Current funding comes primarily from the CDC Division of HIV/AIDS Prevention (DHAP). Additional funding sources include the CDC Division of STD Prevention, the Health Resources and Services Administration (HRSA)-Ryan White Part B funds, and the Washington State general fund.

Evaluation

We are still developing the evaluation of our linkage/re-engagement activities. We have identified a number of performance measures which we use to measure our success at both finding out-of-care cases and linking/re-engaging them with HIV care. Here is a partial list of indicators that will be used to measure program performance:

<u>From HIV surveillance system:</u>

- Number of new HIV cases who meet "in care" definition (based on reported labs)
- Number of new HIV cases with suppressed viral load within the past 12 months

From new Locating Out-of-Care Cases (LOOC) data system:

- Number of potentially out-of-care cases (based on available lab data) that are actually residing in Washington and out-of-care
- Number of out-of-care cases contacted, offered linkage/re-engagement services (e.g., CAPP)
- Number cases that are successfully re-engaged with care

Disseminating Programmatic Information

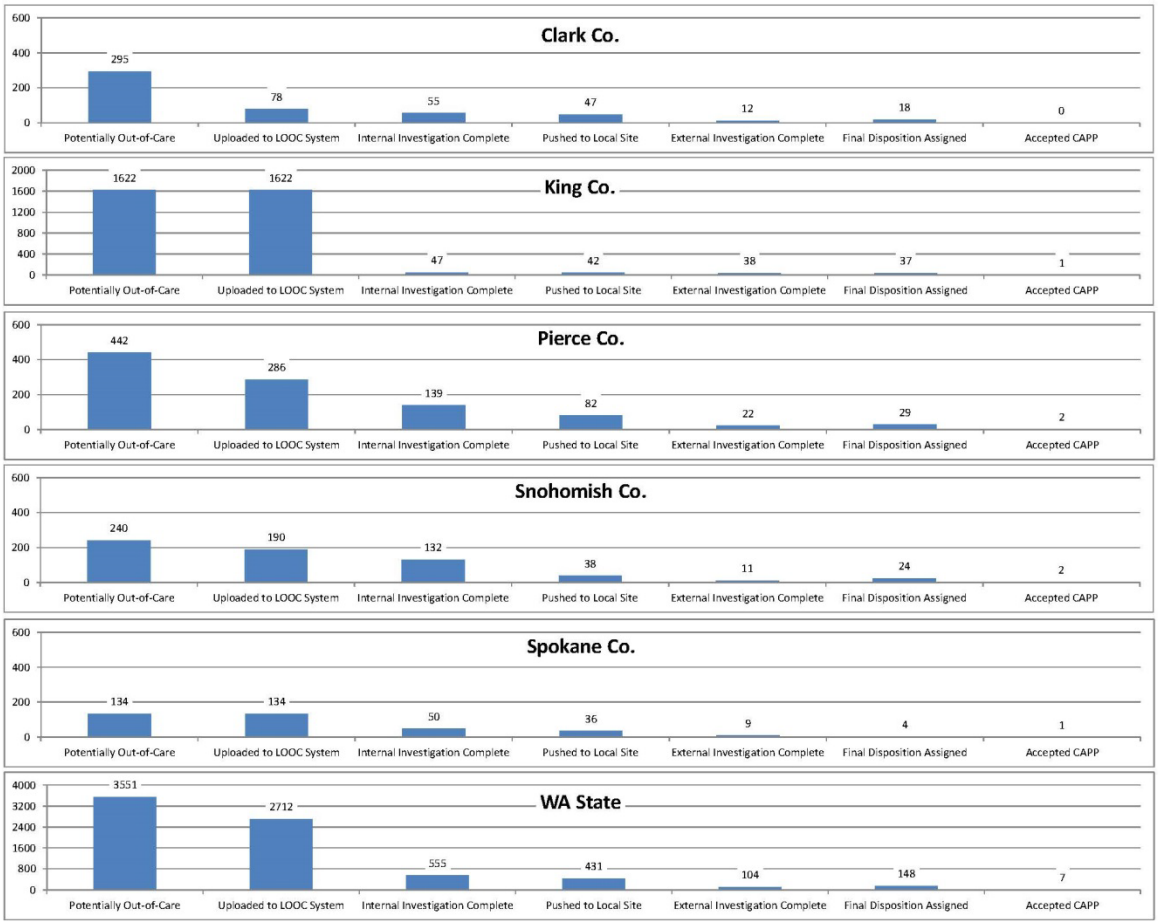
We use various methods to communicate with state and local partners. These include email, regular conference calls, site visits, and written reports, some of which can be produced directly from our LOOC and CAPP data systems. DOH provides training and technical assistance to partner agencies. DOH frequently convenes statewide meetings and consultations around major policy and program decisions. The DOH website contains current epidemiological data and program information for all sections of the office. The following table and figure provide examples of tools we are using to describe progress toward achieving Category C linkage/re-engagement goals.

Table 1. Upload and Investigation Status of 3rd Q. LOOC Cases,* by Current Residence (eHARS) Inside vs. Outside King County and HIV Care Status, as of September 30, 2013

eHARS Current Residence:	Inside King County			Outside King County			Statewide		
Case Status *HIV Care Status:*	No Labs	Marginal Labs	Total	No Labs	Marginal Labs	Total	No Labs	Marginal Labs	Total
Identified as Possibly Out-of-Care	1221	401	1622	1676	253	1929	2897	654	3551
Uploaded to LOOC System	858	292	1150	723	101	824	1581	393	1974
In-House Investigation Complete	41	6	47	435	73	508	476	79	555
Pushed to local health jurisdiction	39	6	45	314	72	386	353	78	431
to King County	38	4	42	64	32	96	102	36	138
to another WA county	1	2	3	250	40	290	251	42	293
Local Investigation Complete	33	4	37	56	11	67	89	15	104
Final Disposition Assigned	36	4	40	96	12	108	132	16	148
Accepted CAPP	0	1	1	2	2	4	2	3	5

* based on 12-month surveillance period between Octoberr 1, 2012 and September 30, 2013; data query on November 13, 2013

Category C - LOOC Site Comparison Report
November 2013
(based on October LOOC list)



Provider Involvement

DOH is working with a network of partners from local health jurisdictions and CBOs in order to make linkage/re-engagement services available statewide. Because these activities are driven predominately by laboratory evidence, linkage/re-engagement activities are initiated by local DIS with the cooperation, if possible, of the last health care provider of record. If a reported case appears to have a gap in care, DIS will investigate to determine if the case in still actively engaged in care. In some cases, labs are not reported to DOH for legitimate reasons, such as labs done for insurance purposes or those associated with research study protocols. In other cases, reporting gaps exist that must be addressed and corrected. Based on the circumstances, DIS may offer direct assistance to clients to re-engage them to care, or refer clients that are eligible and willing to CAPP. Some CAPP specialists are employed by local health jurisdictions, while others work at AIDS service organizations.

Community Engagement

DOH uses multiple methods to engage communities and service partners in the development of strategies and programs intended to achieve a reduction of new HIV infections in Washington State.

The IDPS and HIV Client Services programs routinely work together to facilitate integrated community planning and advisory groups that advise DOH on overall prevention and care strategies, system objectives, service standards, and program policies. All planning processes are open to the public with opportunities for public testimony and comment. Proceedings of all planning groups are available on the DOH website. DOH regularly consults with partner agencies to evaluate current services and support innovation, and convenes local meetings with service providers to discuss community needs and future directions. DOH issues regular HIV and surveillance reports to the public and health care providers.

Partnerships

Partnerships within OID are described above. The Office is housed in the Disease Control and Health Statistics Division of DOH, which includes the state Public Health Laboratory. DOH maintains active relationships with local health jurisdictions throughout Washington and an extensive network of community service providers, including medical care providers, AIDS service organizations and other CBOs, community health clinics, medical case managers, the AIDS Drug Assistance Program, insurance plans serving PLWH, the state Department of Social and Health Services, and the state Healthcare Authority. DOH and the Office of Infectious Disease also have significant partnerships with the University of Washington in Seattle, and the Northwest AIDS Education and Training Center. The OID also partners with pharmaceutical companies and pharmacies in the course of implementing programs for expanded HIV, adult viral hepatitis, and STD testing and treatment initiatives.

Legal and Regulatory Matters

Specific statutes and administrative codes govern the responsibilities of DOH for responding to infectious disease in general, and HIV in particular. Confidentiality and data protection has a prominent place in this regulatory construct. These protections are implemented through state governmental and department-specific systems for safeguarding data and restricting access to all confidential information. Washington state statutes and administrative codes allow data sharing for essential public health functions such as disease investigation and partner notification, establishing a basis for surveillance information to be shared internally and with local health departments. In cases where an out-of-care investigation by a DIS results in referral to a community provider for linkage/re-engagement services, consent for the referral is obtained from the client prior to the referral. The Washington Administrative Code (WAC) was recently revised to permit routine HIV testing in clinical settings without separate consent, but the existing regulatory and technical infrastructure to support sharing surveillance data for linkage to care activities has proved adequate for this purpose.

Training

DOH directly provides or brokers a wide variety of routine training and intensive specialized training in support of program initiatives. Directly provided training includes HIV testing, ARTAS, medical case management training, HIV and STD partner services training and case consultations, and training to use DOH required data reporting systems. DOH staff members also provide site reviews and evaluation training to subcontractor agencies. Brokered training includes a range of trainings provided by CDC and HRSA partners and contracted technical assistance providers. DOH also participates in or sponsors training provided by the Northwest AIDS Education and Training Center.

Program-related resources

http://www.doh.wa.gov/home.aspx

http://www.doh.wa.gov/DataandStatisticalReports/DiseasesandChronicConditions/HIVAIDSData

http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/HIVAIDS.aspx

http://depts.washington.edu/nwaetc/

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