
Using Surveillance and Other Data to Improve HIV Care Linkage and Retention

*A report from a
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Introduction

On November 6 and 7, 2012, Project Inform brought together 30 HIV community advocates and public health officials as a “Think Tank” to explore a number of questions regarding the active use of laboratory data (e.g. CD4 count and viral load)—collected by many departments of public health—to identify individuals who either were never linked to HIV care or who fell out of care. Based on this data, efforts would then be made to link those individuals to health care and other services.

The Think Tank was a timely addition to national discussions about the degree to which public health departments may use surveillance and other data more actively than in the past to promote the health of people living with HIV and to prevent ongoing transmission. In fact, a number of jurisdictions in the United States and its territories already have projects that use collected data for HIV care linkage and retention purposes underway or in the planning stages. Essentially, jurisdictions are using surveillance and other data for care linkage and retention purposes in three ways:

1. Direct outreach to health care providers and community-based organizations to advise them that a patient or client may be out of care;
2. Electronic linkages between surveillance databases and the electronic medical records of large health care systems; and
3. Direct outreach to people living with HIV who have been defined as out of care.

Project Inform convened the Think Tank because, outside of public health agencies and the Centers for Disease Control and Prevention (CDC), there has been relatively little discussion and exploration of these activities by community based organizations and their constituents about the potential for both good and harm that could result from these activities. In fact, since programs of this type were first proposed in the mid-2000s there has sometimes been controversy and community opposition.

Project Inform intended the Think Tank to be an opportunity to educate the community about the legal, ethical and practical challenges involved in these activities as well as the processes that were employed by several health departments in planning and carrying out activities using surveillance and other data for care linkage and retention. In addition, Project Inform wanted to provide an opportunity for community advocates and public

health professionals to engage one another in dialogue about the kind of stakeholder engagement and principles, policies, and procedures that might ensure that the greatest good could be achieved with the least harm.

To that end, the planning committee for the Think Tank formulated a list of critical questions to explore. These included:

1. Could the active use of collected HIV laboratory data contribute in a meaningful way to achieving the goals of the National HIV/AIDS Strategy?
2. Do the benefits of this approach outweigh the risks?
3. If we recommend that additional jurisdictions consider this approach, what policies and procedures should guide their implementation?
4. What things should not be done in furtherance of this approach?
5. Do Think Tank participants support the adoption of legislation in all states mandating the reporting of CD4 and viral load test results to public health departments if only to monitor progress on HIV care linkage and retention?
6. If a department of public health is able to identify those who have never been linked to care or who are out of care, is it ethical not to take action to improve HIV-positive individuals' health and well-being and to attempt to reduce ongoing HIV transmission?
7. Is it the responsibility of the public health department, or individual service providers, to engage in processes to link or re-link HIV-positive individuals into health care and other care supportive services?
8. Do Think Tank participants approve of more active uses of laboratory data (in the abstract) to improve HIV care linkage and retention?
9. If departments of public health were to engage in direct contact with health care providers to call to attention individual patients who are thought to be out of HIV care, what strategies would make such activities least harmful and most acceptable to the community?
10. If departments of public health were to engage in electronic transfer of surveillance data to electronic medical records databases within health care systems to call to attention individual patients who are thought to be out of HIV care, what strategies would make such activities least harmful and most acceptable to the community?
11. If departments of public health were to engage in direct contact with people with HIV to engage or re-engage them in health care, what strategies would make such activities least harmful and most acceptable to the community?
12. Are there community engagement processes and procedures that would be most likely to successfully engage HIV community advocates and health care providers prior to engaging in new uses of laboratory data for care linkage and retention programs?



During the course of the meeting, participants discussed the ethical, legal and practical challenges involved in these activities and developed a list of recommendations to help ensure that when health departments initiate new programs there is sufficient and meaningful community engagement. Participants also formulated policies and procedures to maximize benefits and minimize harms from these activities. Lastly, the group including

AIDS service organizations, academics, health departments and other non-federal agency stakeholders voted on and unanimously accepted a consensus statement affirming that the potential benefits of these activities are sufficient that stakeholder engagement should take place. These recommendations and the full consensus statement are contained within the report.

Background: The Challenges

Before enumerating the recommendations of Think Tank participants it is important to understand the drive to locate and re-engage those out of care and the consequences of not doing so. In July 2010, President Barack Obama made history by introducing the first National HIV/AIDS Strategy (NHAS)¹ ever produced for the United States. This is notable in that since 2003 other countries that received funding for HIV services through the United States President's Emergency Plan for AIDS Relief (PEPFAR) were required to put such a plan in place in order to qualify for funding.

At the White House press conference, where activists and policy makers gathered together to celebrate the introduction of the plan, President Obama laid out the NHAS's key goals:

- to reduce new HIV infections;
- to increase access to care and improved outcomes for people living with HIV;
- to reduce HIV-related disparities and health inequities;
- to reduce HIV-related stigma; and
- to achieve a more coordinated national response to the HIV epidemic.

Though most people understood that it would take hard work to meet these goals, none could have predicted the enormity of the challenge laid out just over a year later by two scientific papers estimating the linkage and retention in health care of HIV-positive individuals in the United States, and the degree of viral suppression of those on treatment.

In the first paper, Edward Gardner, from the Denver Department of Health, and his colleagues,² projected that of the 1.1 million individuals estimated to be living with HIV in the United States only 59% were linked to care and just 39% were retained in care. Of the 350,000 individuals estimated to require antiretroviral (ARV) therapy only 75% were actually on treatment, and of those on treatment fully 20% did not have fully suppressed virus, leaving them open to both HIV- and non-HIV-related health problems, and making it more likely that they could pass on HIV to others. Given that Gardner's figures were based on old treatment guidelines suggesting treatment at 350 CD4 cells (new guidelines recommend treatment for anyone regardless of CD4 count), the number of people requiring HIV treatment who are not receiving it, and even worse the number with suppressed virus is far lower than it ought to be.

The CDC released a second comparable set of data in July 2012.³ In the CDC analysis, of the 1.1 million infected with HIV in the United States, just 37% were estimated to be retained in care, 33% were being prescribed ARV therapy, and only 25% had fully suppressed HIV. Rates of care retention and viral suppression were even lower for younger people, and for African Americans and Latinos. This is particularly concerning given that a recent paper published in *The Lancet*⁴ hypothesized that lack of access to affordable quality healthcare among African American men who have sex with men (MSM) is a key driver behind the sky-rocketing incidence and prevalence of HIV in that community.

Much remains to be done to ensure that when a person receives an HIV-positive diagnosis he or she immediately linked to health care—preferably quality health care and necessary supplementary support services, such as housing, nutrition services, mental health care and treatment for substance abuse disorders. Just as challenging, however, is retaining people in care once a successful linkage has been made.

There are multiple reasons that people fall out of care. Nearly one third of people with HIV are estimated to have no health insurance,⁵ and

many do not qualify for Ryan White health care, which is a payer of last resort. Moreover, even with supplementary funding from Congress, the AIDS Drug Assistance Programs (ADAPs) have not fully eliminated waiting lists to receive free medication, and in some states waiting lists were only closed out after those states made it more difficult to qualify for the programs.

Additionally, the overlapping syndemics of HIV, poverty, substance use and other mental disorders, aggressive incarceration of black and Latino males for petty offenses, homophobia, racism and domestic violence have made it exceedingly difficult for HIV-positive individuals who suffer under these conditions to remain engaged in health care, or to find health care that is sensitive to their needs.⁶ In fact, Laura Bogart, PhD, from Harvard Medical School, and Somnath Saha, MD, MPH, from the Oregon Health and Science University, and their colleagues found in separate studies^{7,8} that experiences of perceived racism within the health care system were a primary driver of not receiving and adhering to ARV therapy.

Clearly, more needs to be done to meet the challenges laid out in the NHAS.

Background: Examples of Existing Programs

Community-based organizations (CBOs) have been retooling to bring their programs into accordance with the NHAS, as have public health departments. Among the most aggressive approaches are those being taken under an HIV Prevention Trials Network (HPTN) grant in Washington, D.C. and the Bronx in New York City, dubbed HPTN 065 or Testing and Linkage to Care-Plus (TLC-Plus).

In those programs, HIV-testing staff is responsible to make a linkage to care within 24 hours of a positive diagnosis. Once that linkage is made, some individuals are offered monetary compensation for remaining successfully in care and maintaining full viral suppression. Other cities are attempting similar approaches.

In Massachusetts, where there exists nearly universal health care, rates of retention are estimated to be at an exceptionally high 95% to 99%, with viral suppression rates exceeding 70%.⁹ In San Francisco, which similarly seeks to offer care to all city residents, retention and viral suppression rates are both approximately 50% through 2011.¹⁰ Yet even in these cities, which have extraordinary resources compared with many of the most impacted communities in other parts of the country, care linkage and retention is not perfect.

For this reason, the CDC and many local health departments have been exploring other methods to locate those who were never linked

to care, or who fell out of HIV care along the way. One promising avenue is the use of laboratory data already being collected for surveillance purposes (e.g. CD4 count and viral load), as well as databases from Medicaid, Medicare, Ryan White and private insurers, not only as a proxy for understanding rates of care linkage and retention but as tools to discover those out of care and take action to bring them into it.

Several such programs are explored in depth below but, in essence, there have thus far been three primary models for the utilization of collected laboratory data, as previously mentioned.

In the examples immediately following, public health experts have chosen to take one or more of these types of actions in furtherance of the health and well-being of people living with HIV, and secondarily to attempt to reduce HIV incidence. Three geographic areas are profiled: Washington, D.C., the state of Louisiana, and King County in Washington state.

WASHINGTON, DC

Collected laboratory data is used for several purposes in this jurisdiction, both passively (to simply track the epidemic) and actively (to intervene where lapses in care are found). At heart, this data allows public health experts in D.C. to track how well providers in the city are doing with respect to HIV care linkage and retention, and therefore how closely the city is meeting the goals of the NHAS. More recently, however, the city chose to adopt procedures whereby the city directly engages with health care providers and CBOs regarding the care and health status of individuals cared for by those institutions.

How it works:

Designated as a “Recapture Blitz” by the D.C. Department of Health, the program operates in two directions. Providers are asked to send lists to the HIV/AIDS, Hepatitis, STD, and TB Administration (HAHSTA) of the public health department of patients who have disappeared from care for at least six months. HAHSTA matches those names with its own database to determine which individuals are actually out of care compared with those who may have died or who have simply engaged in care at another location. Data systems include electronic laboratory data, ADAP enrollment and eHARS (HIV surveillance). Once the match is complete, each provider receives a dataset based on the information provided to HAHSTA to say either, “Yes this person has been engaged in care at another location,” or, “No, this person is not engaged in care.”

For those found to be out of care, each CBO or provider attempts to make direct contact with the clients to re-engage the person within 90 days. The DC program does not limit the number of contacts. In some instances, a provider may have contacted the individual as many as 13 times to re-engage the client.

HAHSTA also uses surveillance data to actively link people to care. One such program is the Strategic Multisite Initiative for the Identification, Linkage and Engagement in Care of Youth with Undiagnosed HIV Infection Linkage-to-Care (SMILE). To ensure that all youth (ages 12-24) diagnosed with HIV are linked to and engaged in HIV clinical care, HAHSTA collaborates with the Children’s National Medical Center as well as five other youth service providers to use surveillance and lab data to verify linkage to care among newly diagnosed youth under the age of 25.

HAHSTA also creates reports documenting the success of providers in retaining individuals in care and ensuring viral suppression of those on ARV therapy.

History of community engagement:

Officials at HAHSTA began working with several community-based providers in 2009 to develop active data use strategies. Family Medical Counseling Service (FMCS) began its care linkage and retention program independently in 2009. HAHSTA approached FMCS and

invited other providers to discuss potential best practices. During this stage, topics of discussion included logistics of data matching, security and confidentiality and strategies for engagement, monitoring and evaluation.

A few months later, the D.C. area began to pilot a new district-wide program. Data from the program indicated that more than 300 people were re-engaged in care. As the pilot proved successful, HAHSTA further engaged with key health care providers and CBOs in the city to determine how best to scale up the program. This activity is now part of Ryan White Part B funding. The match is also conducted upon the request to the HAHSTA strategic information program. Given the active ongoing coordination and collaboration with providers, HAHSTA is able to determine the acceptability of this intervention among providers and CBOs, and it reports that the program thus far has achieved high levels of acceptability and that providers are appreciative of the services provided by HAHSTA.

Engagement with CBOs also influenced the selection of the DC model in the SMILE protocol. While 15 other jurisdictions conduct SMILE, DC is the only jurisdiction using a model that focuses on the use of surveillance data to evaluate real-time linkage to care and to direct client engagement and follow-up by providers and CBOs conducting testing, linkage and retention activities.

Surveillance data can also be used in aggregate to answer important questions. When the TLC-Plus study was launched in Washington, D.C. some in the community raised concerns that this program—which offers intensive care linkage and treatment for those found to be HIV-positive—would be “forcing people onto treatment.” In analyzing surveillance data, however, HAHSTA found that 55% of all of individuals receiving a new HIV diagnosis between 2005-2009 had CD4s of 500 or less, making them immediately eligible for treatment according to 2011 U.S. Department of Health and Human Services (DHHS) Treatment Guidelines at that time. Given that current ARV treatment guidelines recommend treatment for all “ready” HIV-positive individuals, regardless of CD4 count, the strategy to offer treatment to all is consistent with those guidelines. The sensitivity with which treatment should be offered, and how individuals who choose not to start ARVs should be supported, was outside the scope of this Think Tank. It should, however, be an active topic of discussion between providers and the community.

LOUISIANA (LaPHIE):

Funded in 2007 by a Special Projects of National Significance (SPNS) grant from the Health Resources and Services Administration (HRSA), collaborators from the Louisiana Department of Health and Hospitals Office of Public Health (OPH) and the Louisiana State University (LSU) hospital system sought to build an information exchange program

between the public health department and the state's largest provider of HIV care, to address the problem of missed opportunities to provide HIV care linkage and improve retention.

How it Works:

The Louisiana Public Health Information Exchange (LaPHIE) is a collaboration between the LSU, the OPH and the Louisiana Public Health Institute. The OPH first uses reportable laboratory data to create a dataset of persons who either were never linked to care following an HIV diagnosis or have fallen out of HIV care. Through a privacy protected data exchange system with the electronic medical record (EMR) system of eight LSU hospitals' emergency rooms, outpatient and inpatient settings, the OPH embeds a message into a patient's EMR about their HIV care status.

- When any patient registers at an LSU hospital, his or her identifying information is added to the LSU computer system.
- LSU electronically notifies the OPH (via LaPHIE) that the patient has arrived at an LSU facility, by securely sending a message with minimal patient identifiers to a secure, designated LaPHIE server housed at the OPH.
- When the OPH receives a message from LSU, the LaPHIE logic checks its "out-of-care" patient dataset to determine if the patient is listed there.
- If the OPH finds a match in the out-of-care dataset, it automatically sends

a standard, disease-specific electronic message to the LSU EMR system. For instance, that a person may never have received their HIV test results or that no viral load or CD4 count is on record within a specified period of time.

- The LSU system receives and stores the message from the OPH. It then displays the message as a pop-up alert for authorized clinicians who open the patient's EMR within the visit timeframe. When a clinician clicks on the alert, he/she sees a list of suggested actions, which can be checked off on screen as actions are taken.
- After the clinician visit, the LSU system automatically returns a message to the OPH with current contact information and a report listing the actions taken in response to the message.

In addition to prompting action for people who have been out of care for 12 months, because they never picked up their HIV test results, never got linked to care, or fell out of care, the system also issues alerts for those who tested positive for syphilis or tuberculosis (regardless of HIV status) who do not appear to have completed treatment.

History of Community Engagement:

Sharing protected health care and public health information is a complex (but solvable) technical problem. Yet implementing a system like LaPHIE raises many non-technical challenges and questions. Under

what circumstances is it legal to share health information between health care providers and public health professionals? Is it ethical? Is building a system like LaPHIE the right thing to do in terms of protecting the health of individuals and the health of the community as a whole?

To address such questions before building the exchange, the LaPHIE partners created a legal compliance and ethics workgroup consisting of public health officials, HIV-positive individuals, doctors and nurses, attorneys familiar with federal and state health laws, HIV advocates, and a medical ethicist. Over the course of a year, the workgroup developed a list of legal questions to be answered, reviewed relevant legislation, and discussed plans for an exchange with national experts in confidentiality and biomedical ethics. The group also enlisted the expertise of an independent market research firm charged with conducting interviews and focus groups to gather information on how potential patients would view the project.

Based on this legal and ethics analysis, the workgroup concluded that the LaPHIE project ought to be implemented because it worked to protect both individual and population health. They also found that, in Louisiana, there were no laws prohibiting information sharing for the purpose of improving individual care. In fact, the group found Louisiana legislation that facilitated

communication between public health authorities and health care providers to improve treatment.

These conclusions were fortified by the focus group and interview results from Louisiana residents, many of whom were HIV-positive, in which surveyed individuals showed support for the sharing of protected information with nurses and doctors if the purpose was to give patients information and provide improved health-care. To date, HIV-positive individuals identified by LaPHIE have not expressed objections to the system, and it has even been described in an evaluation interview as a “good system.”

KING COUNTY, WASHINGTON STATE:

The department of public health in King County, which includes the city of Seattle, has chosen to employ one of the more controversial methods for ensuring HIV care linkage and retention: direct contact with HIV-positive individuals who have been identified as not linked to care, or not retained in care. The department, however, understanding the sensitivities around such activities did engage actively with both health care providers and people living with HIV before launching their project.

How it works:

The surveillance branch of the King County Department of Public Health periodically reviews data on individuals reported to be

HIV-positive. Laboratory data are included in this analysis and individuals who have never had their CD4 or viral load tested, or who have no lab data for at least 12 months, or had a CD4 count ≤ 500 and viral load > 500 at the time of last report, are designated as possibly out of care.

As a preliminary step to direct contact, a King County Department of Public Health Disease Intervention Specialist (DIS) first reaches out to the healthcare provider of record to offer the provider an opportunity to opt-out of the program on behalf of individual patients. If the provider requests that the DIS worker not contact the individual, no direct contact is attempted.

If the provider approves of a direct contact, a DIS follows up using contact information provided at the time of the last contact or HIV test. The DIS workers assigned to this project focus solely on HIV care re-engagement activities and are selected for demonstrated ability to establish rapport with PLWHA and HIV providers and effectively work with hard-to-reach individuals. The first DIS hired to do this work is a peer who is open about his HIV status with program participants when contextually appropriate. A second DIS with similar skills in reaching the most vulnerable populations was hired in the fall of 2012.

A very specific script is used at the initial phone attempt to protect privacy and con-

fidentiality. In the initial contact, no mention is made of HIV status or any other communicable disease. Instead, individuals are told that the health department is conducting a new program, and that for a \$50 stipend, people are being asked to come in for interviews regarding the program. If the person being sought is available to speak by phone, further information about the reason for the call and the nature of the interview are provided.

If a person consents to be interviewed in person the DIS ascertains the primary reasons that a person may be out of care and helps to guide them toward resources that may help them re-enter and remain in care. After the interview, the DIS sends summaries of the encounter to the participant's medical provider and case manager if the participant consents.

History of Community Engagement:

The King County Department of Public Health went through several periods of direct engagement with both people living with HIV and HIV care providers to determine the acceptability of the program concept and obtain feedback to guide development of the program. During the process both one-on-one interviews and focus groups were conducted.

During these interviews and focus groups the majority of people living with HIV indicated that they found it acceptable

to be contacted for this purpose by the department of public health, that they would view the program as another source of support for their care, and that they thought it would be good for the health department to “make sure no one falls through the cracks.” Many did indicate, however, that they felt “other people with HIV” might object to the service even when they themselves did not.

Interestingly, those most opposed to this service were HIV medical care providers. Although medical providers had a range of opinions, varying from very supportive to neutral to negative, several were concerned about the program concept when interviewed between 2009 and 2010. The most common reasons for objecting were that the program had the potential to negatively impact the patient-physician relationship by delivering messages that could counteract or seem to counteract information the providers had discussed with their patients, that patients would be opposed to an invasion of their privacy, and that the health department was overstepping its bounds and should have higher priorities than conducting this program.

PROGRAM OUTCOMES

Data are still emerging on these three programs, all of which are relatively new. Officials from Washington, D.C. have previously reported at meetings that roughly one quarter of those who were found to be out of care were successfully reached by providers and kept a medical appointment after entering the Recapture Blitz program.

In Louisiana, the LaPHIE system issued 549 alerts between February 2009 and July 2011, identifying 419 HIV-positive individuals. Nearly one-quarter had not had a CD4 count or viral load test since diagnosis. Of the remainder, nearly half had been out of care for at least 18 months. Following the alert and intervention of the provider, of 344 patients who had at least six months of follow-up, 85% had at least one CD4 count and/or a viral load test after being identified.

In King County, data from the pilot phase of the program were recently reported. Of 260 eligible individuals, health care providers allowed the public health department to contact 194 of them. The health department was able to successfully contact 113 of whom 75 completed an initial intervention designed to identify and address issues that led the individuals to be out of care.

Background: Ethical and Legal Considerations

Ethics:

Public health surveillance began near the end of the 19th century primarily as an effort to track the spread of disease within a given geographic area or demographic community. Early strategies evolved, however, so that the passive collection of data morphed into proactive efforts to contain the spread of disease. In the middle of the 20th century, public health authorities began tracking chronic non-infectious illnesses such as cancer. Though public health activities have evolved to adopt greater ethical standards for the protection and privacy of individuals about whom data are collected, there remains a tension between individuals who predominantly favor only passive collection and reporting of health information versus those who favor more active applications of data for the control of diseases as diverse as syphilis and diabetes.¹¹

The Public Health Leadership Society (PHLS)—an association of senior public health professionals devoted to providing leadership and guidance to public health workers and government public health agencies—has published ethical guidelines¹¹ for public health officials. The tension between passive and active uses of data are directly referenced in the guidelines by the statement that, “People are responsible to act on the basis of what they

know. Knowledge is not morally neutral and often demands action.”

Specifically, when does the knowledge of illness in an individual or community acquire sufficient certainty that it would be unethical not to use collected data for promotion of health in an individual or to protect the health of others?

This question isn’t always easy to answer, but the pendulum has begun to swing in recent decades from those favoring only passive surveillance to those favoring intervention. This is largely due to new technologies that make it possible to quickly and accurately document specific health problems—ranging from unsuppressed HIV levels indicating HIV care status and lack of treatment success to elevated A1C levels, indicating poor blood sugar control in diabetics. The ethical question therefore tilts from whether it is ethical to intervene with providers and patients to whether it is ethical not to intervene if one has such important knowledge about the health of his or her citizens. To ensure that such action is ethically balanced and acceptable to the individuals about whom the actions will be taken, the PHLS has developed a list of requirements for public health activities, a few of which are listed below:

- Public health should achieve community health in a way that respects the rights of individuals in the community.
- Public health policies, programs, and priorities should be developed and evaluated through processes that ensure an opportunity for input from community members.
- Public health should advocate and work for the empowerment of disenfranchised community members, aiming to ensure that the basic resources and conditions necessary for health are accessible to all.
- Public health institutions should provide communities with the information they have that is needed for decisions on policies or programs and should obtain the community's consent for their implementation.
- Public health programs and policies should incorporate a variety of approaches that anticipate and respect diverse values, beliefs, and cultures in the community.
- Public health programs and policies should be implemented in a manner that most enhances the physical and social environment.
- Public health institutions should protect the confidentiality of information that can bring harm to an individual or community if made public. Exceptions must be justified on the basis of the high likelihood of significant harm to the individual or others.
- Public health institutions and their employees should engage in collaborations and affiliations in ways that build the public's trust and the institution's effectiveness.

Programs, such as those implemented in D.C., Louisiana and Seattle/King County do not come without risks for harm to individuals, to relationships between health departments and providers and to entire health care systems.

On an individual level, potential harms are varied and depend a great deal not only on the intervention being used, but also on how interventions are employed. As one advocate said whom Project Inform interviewed in the lead-up to planning the Think Tank, "The devil is in the details."

Perhaps the most intensive harms that could occur if laboratory records are used for care re-engagement are those that arise from efforts by health departments to contact individuals directly.

Some programs using DIS workers are better conceived and run than others and operate with greater sensitivity to the potential for harms. Without sensitivity to the particular circumstances of HIV-positive individuals at risk of domestic violence, for instance, any activity that might result in the disclosure of the individual's HIV status could result not merely in injury, but even death. As the recent murder of Cicely Bolden in Texas made clear, when violent and unstable individuals learn of the HIV-status of their sex partners the results can be deadly.

Likewise, harms to undocumented individuals may potentially be great, particularly for those in situations where widespread knowledge of their HIV status could jeopardize their housing and community support, two things immigrants to the United States, in particular, depend on quite heavily to merely survive.

Finally, if DIS workers act without sensitivity in their efforts to track down and re-engage individuals who are out of care, there is a significant risk of increasing HIV-related stigma, which studies have revealed is a prominent reason that individuals fail to get linked to care or to remain in care.¹³ Inadvertent disclosure with potential for stigma harm can also occur in the course of intervention by staff of clinics and CBOs, especially those serving multiple health conditions and/or in cramped conditions that impair privacy.

Programs that are set up to notify clinicians and workers at CBOs also have the potential for harm. If tracking of patient outcomes is used in a fashion to punish providers with larger percentages of patients out of care this can result in a degradation of relations between health officials and providers, a relationship that is vital if public health is to be adequately promoted.

This is particularly true if funding decisions are tied directly to levels of HIV care retention and/or viral suppression. While accountability is important, it also runs the risk of punishing those who choose to work with the most

challenging populations or in the most challenging geographic locations. As the battles over public education reform have made clear, it can be far too easy to disrupt tenuous safety nets in impoverished communities in the zeal for improved accountability.

The Law

The legal considerations specific to active uses of collected laboratory data fall into two categories: requirements to report such data to departments of public health and whether such information may be shared outside the departments.

In the early years of the epidemic, the grave harms that rose out of the revelation of a person's HIV status—not limited to loss of jobs, homes and loved ones, but also physical violence—as well as the high degree of stigma associated with the disease led many individuals to go without being tested for HIV or even electing to seek medical care. In order to better ensure people's well-being, and to encourage HIV testing, many states adopted strict confidentiality and privacy laws, as well as laws explicitly allowing anonymous testing. As well, for roughly two decades an AIDS diagnosis, but not an HIV diagnosis, was a names-based reportable illness in many states.

As stated above, the traditional reasons to report illnesses rose out of attempts to control the spread of highly infectious diseases. In more recent times health departments have dramatically added programs to address chronic non-infectious health conditions in

addition to communicable diseases. HIV, along with other STDs, fall somewhere in between as it is not the public at large, but only the sex and drug-using partners of those infected who risk becoming infected themselves.

As for laboratory data, 34 states, 2 territories and the city of Philadelphia also currently mandate the reporting of all values of CD4 and viral load results to departments of public health in addition to HIV diagnoses. At the time that such statutes were put in place, however, the primary purpose was to monitor clinical HIV disease outcomes. Active uses of such data were not always considered when these laws were put in place and in some cases were explicitly disavowed as part of the process for gaining buy-in to name-based case and laboratory reporting. It is likely that community advocates for those laws would not consent to or approve of the ways that such data are now being used.

Another important legal consideration is how data on individuals living with HIV may be shared outside the public health department. The Health Insurance Portability and Accountability Act (HIPAA), which mandates that individuals must provide written consent for the sharing of their private medical information as well as various state laws protecting the privacy of health information, provides a legal framework for protecting and sharing health data. HIPAA explicitly states that where state laws are more protective than HIPAA, then state laws control the transfer of such information.

There are provisions within the HIPAA legislation allowing for the sharing of collected personal health information “to a person who is at risk of contracting or spreading a disease or condition where state law authorizes the disclosure as necessary to carry out public health interventions or investigations.” Moreover, most current activities where information about laboratory data is provided to professionals outside the department where it has been collected do not actually involve sharing information that is not already known or accessible to the health care professional being contacted.

For instance, in Washington, D.C., HAHSTA is simply alerting a medical care provider that no new laboratory data has been collected within a six-month time frame. This information is generally already available to the provider unless a person has transferred their healthcare to a different provider. While the specific activities undertaken by the LaPHIE program differ from these examples, legal experts consulted by the program determined that those activities do not run afoul of either HIPAA or any state laws in place regarding the collection and maintenance of HIV-specific information by the department of public health.

In other states, such as Massachusetts and California, the boundaries of state law regarding sharing of data related to HIV and other sensitive data are less clear, despite recent legislative updates.

A remaining issue that deserves special emphasis is the criminalization by 32 U.S. states and territories of the failure to disclose HIV status during sexual encounters, often regardless of whether there was any real risk of transmission. Such laws are a travesty, and have resulted in significant harms to thousands of people living with HIV globally and well over 1,000 within the United States since such laws were first implemented. Beyond the harm to individuals who are charged, these laws and related enforcement policies contribute greatly to the stigmatization of people with HIV, which in

turn makes it significantly more difficult to engage and maintain HIV-positive people in care.

In some cases where individuals have been charged with a crime, law enforcement officers have subpoenaed public health departments for confirmation of HIV status. It is conceivable that authorities might subpoena CD4 or viral load data to support or enhance criminal charges related to sexual activity or non-disclosure. Health departments should consider these kinds of risks as they go about designing new public health interventions.

THINK TANK RECOMMENDATIONS

The Think Tank participants were asked to engage in six separate discussions to answer the questions laid out at the beginning of this report. Those six discussions included:

- defining policies and procedures for each type of activity that would reduce risks and enhance benefits;
- defining stakeholders who should be consulted during the planning and execution of activities as well as describing what meaningful engagement would look like;
- identifying further how local jurisdictions should contend with the need for innovative care linkage and retention activities;
- identifying actions and priorities for advocates and others to forward these issues on a national level;
- developing and voting on a consensus statement regarding the use of surveillance data and other data for care linkage and retention; and
- defining issues for further follow-up and exploration.

A survey conducted prior to the Think Tank identified many of the concerns that were later addressed during these discussions. At the meeting's outset, a number of community advocates expressed serious reservations about using collected surveillance and other data in the ways described earlier in this report. Those concerns are described below as well as recommendations to help address them.

Policies and Procedures

Workshop participants were challenged to enumerate the potential risks and benefits of each type of approach mentioned above to find those out of care. These included: direct provider contact; electronic information exchanges, and direct patient contact.

In summary, the most frequently cited concern was that “one size does not fit all.” In other words, whatever approach or approaches are employed must be sensitive to the circumstances and needs of a local jurisdiction. For instance, activities with greater risks for harm, particularly in some communities or parts of the country, may actually be considered favorably in cities or counties with long-lasting and positive relationships between public health departments, providers and the community, but not favorably in areas where there has been difficult or minimal relations between all stakeholders or where HIV-related prosecutions are more prevalent.

Another overarching recommendation was that health departments, where it is legal and feasible, should consider using multiple sources of data in assessing who is out of care. Non-surveillance data could include Ryan White data and Medicaid databases.

Another key concern stressed, regardless of the approach being considered, was the need for early, extensive and meaningful stakeholder engagement before launching a program, with a particular emphasis placed on the need for engagement with people living with HIV. Such

engagement must not stop, however, as soon as a program is launched, but instead should be part of program evaluation and quality improvement. Meaningful engagement is defined in the next section and specific recommendations are included as well.

There was a sentiment among community advocates at the Think Tank that the approach most likely to enjoy support from the community and the least likely to risk harms is direct outreach by health departments to HIV care providers. Conversely, the greatest amount of concern was for programs where DIS workers are used by health departments to directly reach out to people living with HIV who appear to be out of care. If direct contact with patients is employed as a strategy, however, Think Tank participants felt that the best model would be the use of a peer care coordination or navigation model and that emphasis should be placed as much on meeting the social service needs of those who are out of care as in getting them into see a health care provider.

Lastly, the sentiment was expressed by some that technological tools being utilized by private insurers and other for-profit health care entities are far superior to those available to many public health departments and that funders, policy makers and advocates should keep this in mind when prioritizing resources for system upgrades.

Specific risks, benefits and considerations for each of the three primary approaches are listed in detail here.

Direct outreach to providers

POTENTIAL BENEFITS

- If done properly this could significantly improve the health and well-being of people living with HIV who have fallen out of care.
- This could be among the least expensive of the three types of activities.
- Of the three types of activities this has the advantage of being the least likely to result in coercion of patients.
- Of the three types of activities this is most likely to be accepted by the community.
- Such efforts take advantage of existing relationships between providers and patients and this could strengthen those relationships. Provider effort to reach out to patients could lead at least some patients to feel better cared for by providers.
- Enhancing relationships between public health and providers not only maximizes the use of data, but also can actually improve the quality of the data through bidirectional transfers of information.
- Consent from the patient to be contacted if they fall out of care could be easily obtained at the time of care entry.
- Implementation of this strategy could identify workforce shortages and allow for redirection of funding resources.

POTENTIAL RISKS AND LIMITATIONS

- This approach does not address people who were never linked to HIV care in the first place.

- Many providers currently have limited capacity for follow-up: this approach relies on time and resources from providers and their staff.
- Some providers could feel this is invasive and that the public health department is “grading” them. This could jeopardize relations between public health and providers.
- Providers and their staff don’t necessarily have training in care linkage and re-engagement. If poorly conducted, these activities can breach privacy and increase the risk for stigma.
- Some risk factors for being out of care, such as ongoing substance use or insecure housing, are difficult to solve: simply reaching out to the provider won’t address those problems.
- If public health data is incomplete or out of date it could lead to wasted effort.
- If there are not strict and well thought out protocols for the transfer of information about patients to providers, there could be breaches of privacy.

PRACTICES TO EMPLOY TO REDUCE HARMS AND MAXIMIZE BENEFITS

- Departments of public health (DPHs) should develop goals and a communication strategy about the risks and benefits of this approach before contacting clinicians for feedback and program design.
- DPHs should be consistent in how people are defined as being out of care.

- DPHs should use all means possible to ensure the highest quality data and utilize Institutes of Medicine or Health and Human Services definitions of out of care.
- DPHs should thoroughly and meaningfully engage providers and medical societies to help design and evaluate programs.
- DPHs should utilize AIDS Education and Training Centers to enhance training on care linkage and retention for providers and staff. Those engaging in care re-engagement activities should be trained to be compassionate, caring, respectful and non-coercive.
- DPHs should, where possible, help providers acquire resources and personnel for care coordination activities, particularly if providers are serving vulnerable populations.
- DPHs should limit access of data by the role of the provider (e.g. limit data sharing to providers and support staff who will be taking lead responsibility for care linkage and retention).
- DPHs should ask providers to be transparent with patients about care recapture efforts that will be undertaken if a person falls out of care.
- DPHs should explore the legality and capacity to share data across multiple providers.
- DPHs should prioritize resources toward the most vulnerable patient populations and methods that have the greatest likelihood of success.

Electronic Exchanges

POTENTIAL BENEFITS

- If done properly this could significantly improve the health and well-being of people living with HIV who were never linked to care or who have fallen out of care.
- This approach addresses people who were never linked to care, not just those who have fallen out of care.
- This approach takes advantages of missed opportunities for care linkage and retention and finds people where they are.
- This approach may reduce disparities in health care by re-orienting responsibility for care linkage and retention to multiple provider types.
- This approach allows for the least amount of information about a person to be transmitted outside of the public health department and a more secure protocol for information transmission.
- This approach is narrowly constrained for specific purposes and potentially avoids mission creep.
- If combined with care coordination and social services this approach could have a high degree of success at care linkage and re-engagement.

POTENTIAL RISKS AND LIMITATIONS

- This approach is more complex and resource intensive technologically than programs that reach out directly to providers or those out of care.
- This approach may ultimately be limited to jurisdictions with large public health care institutions that serve a substantial proportion of people living with HIV and that have high quality electronic medical records.
- If poorly conceived or maintained there could be data leakage to those other than direct care providers, such as support staff.
- This approach relies heavily on providers with little to no expertise in HIV appropriately linking or re-engaging people who are out of care.
- People who are out of care could feel that their confidentiality has been breached if an emergency room provider or other non-HIV specialist engages them about their HIV status. This could lead to increased stigma and discrimination.
- If care linkage and re-engagement activities are not tracked closely it could cause public health officials to remove people from out of care lists prematurely.
- HIV care coordination specialists might not be available at the time of care re-entry to aid in addressing the reasons that people were never linked to care or fell out of care in the first place.
- If data are not of high quality it could lead to false alarms.

- The system, especially the specific activity prompts, could be designed too rigid and inflexible to adequately address the best level of provider and patient interaction.

PRACTICES TO EMPLOY TO REDUCE HARMS AND MAXIMIZE BENEFITS

- DPHs should engage multiple stakeholders during the planning process, including information technology and privacy experts, legal and ethics professionals, HIV and non-HIV providers and especially people living with HIV and community advocates. The LaPHIE model is a good model to follow in this regard.
- DPHs should use all means possible to ensure the highest quality data to determine who is out of care and utilize Institutes of Medicine or Health and Human Services definitions of out of care.
- DPHs should consider, if feasible and legal, using multiple sources of data.
- If technologically possible, DPHs should explore an opt-out model at the time of HIV testing or allow people testing to assert what types of information they consent to be shared in an electronic exchange system.
- DPHs should offer or encourage training to the providers who are likely to receive electronic message prompts from the public health department, especially emergency and urgent care providers. This is especially important as individuals who were never linked to care may differ in important ways from those who have

dropped out of care. Moreover, increasing provider knowledge of social service and care coordination services in the community can increase the likelihood that the factors leading to poor care linkage and retention may be addressed.

- DPHs should consider, if technologically feasible, a phased rollout to give time for the program to be tested.

Direct outreach to patients

POTENTIAL BENEFITS

- If done properly this could significantly improve the health and well-being of people living with HIV who were never linked to care or who have fallen out of care.
- This approach addresses people who were never linked to care and not just those who've fallen out of care.
- If using a peer or near-peer care coordination model this could allow for barriers to care to be addressed quickly and adequately by the DIS worker.
- This approach is scalable.
- This approach could more easily locate some of the hardest to reach individuals who are out of care.
- In many jurisdictions this type of effort would be covered under existing DIS protocols.
- Depending on how it is deployed, this effort could reduce the number of hand-offs between medical and social service providers.

POTENTIAL RISKS/LIMITATIONS

- Some community advocates were fundamentally opposed to this approach under any circumstance, citing concerns about privacy, stigma, discrimination and even, possibly, vulnerability to prosecution of those found to be out of care.
- If DIS workers inadvertently breach privacy during the course of attempting contact this could result in severe harms to the person who is out of care.
- If DIS workers are improperly trained they could increase feelings of stigma and discrimination among those out of care. Further, DIS workers may use coercive techniques to try to link or engage individuals.
- This is a resource- and labor-intensive approach to care linkage and retention. Some health departments may not have the resources to employ this type of effort properly or would have to make unacceptable trade offs regarding other public health programs.
- Even if a method to obtain consent to be contacted is employed that consent may later be withdrawn by the person out of care.

PRACTICES TO EMPLOY TO REDUCE HARMS AND MAXIMIZE BENEFITS

- DPHs should engage in extensive consultation with key stakeholders, particularly people living with HIV, community advocates, health care providers and privacy experts during the design process and to evaluate the program after it is launched.

- DPHs should perform cost-analyses to ensure proper funding when determining what types of care linkage and re-engagement processes to employ.
- If technologically possible, DPHs should explore an opt-out model at the time of HIV testing. If this is not possible, DPHs should issue a formal recommendation to those performing HIV testing to inform clients that DIS workers may later try to reach them if the person appears to be out of care.
- DPHs should use all means possible to ensure the highest quality data and utilize Institutes of Medicine or Health and Human Services definitions of out of care.
- If DIS workers are deployed, DPHs should use continuous quality improvement methods to ensure not only the success of the effort, but also the acceptability by providers and patients. Further, DPHs should track and evaluate contact efforts that are made and when a contact is made indicate whether it was positive or negative for the person being outreached to.
- DPHs should consider hiring peers or near-peers as DIS workers and utilize a care coordinator model for these workers. Emphasize connections to services that address barriers to care when contacts are made.
- DPHs should consider reaching out to providers for consent to contact patients and to evaluate data accuracy before reaching out to those out of care.
- DPHs should consider allowing providers to approach the public health department for aid in locating those who have been lost to care.
- DPHs should consider deputizing community-based care coordination experts as health department officials to allow for peer or near peer workers to be utilized.
- DPHs should seriously consider the local reality on the ground including the availability of local social services to address care linkage and retention barriers, the current and historical relationship between the health department and the community and likelihood of criminal prosecution for HIV non-disclosure or exposure.

Meaningful Stakeholder Engagement

Stakeholder engagement is a recommended best practice for many types of public health efforts and this is especially true when it comes to the use of public and private data to enhance HIV care linkage and retention efforts. Stakeholder engagement can be used to define goals and likely barriers, weigh important legal and ethical considerations and identify processes and procedures to minimize potential harms.

Stakeholder engagement procedures can range from private meetings and focus groups to surveys or even open public forums or the provision of time for written public comment on proposed activities.

Simply asking for the input of important stakeholders “late in the game” is insufficient, especially if that input is not likely to be adopted because departments have moved too far along with planning to allow for changes identified during the stakeholder engagement process. For this reason, the participants involved in the Think Tank stressed that not only should stakeholder engagement occur in the development phase, it should be meaningful.

Engagement should occur early in the planning process and health departments should be clear during the engagement process what elements of a proposed project can be changed and which cannot. Participants also recommended strongly that stakeholder engagement be used on a continuous basis even after the launch of programs to ensure quality control,

transparency and proper accountability to stakeholders.

In order to make proper decisions about the use of collected data for care linkage and retention purposes, there are certain activities that participants recommended that certain activities be conducted before engaging stakeholders. These may include:

- assessing the quality of the data to be used and procedures necessary to bring data sources to at least a minimum level of reliability;
- conducting cost analyses of the types of activities being anticipated and identifying potential funding sources and trade-offs if other activities would have to be curtailed in order to implement new programs; and
- developing a list of over-arching goals and communications strategies to ensure that stakeholders can be properly informed about the logistical, practical, legal and ethical issues that may arise from these activities.

STAKEHOLDERS TO ENGAGE

When considering the use of surveillance data and other data for care linkage and retention there are multiple types of stakeholders who should be consulted before, during and after activities are launched. Each brings a unique contribution to ensure that programs are feasible, effective and have limited potential to cause harm to people living with HIV or to their health care providers. Below is a list of potential stakeholders, the types of contributions they can offer to planners and implementers of programs and optimal methods for gaining feedback.

PEOPLE LIVING WITH HIV

Given the nature of HIV stigma, discrimination and even criminalization, both in the past and present, active uses of private medical data have substantial potential for harms. For this reason, it is vital that the concerns and input of people living with HIV be actively sought, especially if the health department plans to have direct contact with people identified as out of care.

It is further ideal if health departments envision people living with HIV as partners in the development of care linkage and retention efforts rather than as passive recipients or subjects of such services. Such a philosophical approach is more than semantic: it can have a powerful impact on the magnitude and quality of the feedback from these vital stakeholders and on the design and conduct of programs.

Focus groups are an ideal way to solicit input from people with HIV during the planning process, because they allow for dialogue, education and clarification. One-on-one interviews offer similar benefits, but are more labor intensive. Surveys may also be employed, and they do offer anonymity and the ability to reach larger numbers of people. They may be preferable for program evaluation than for program planning, however. It should also be stressed that efforts should be made to seek feedback from individuals who are most likely to be directly impacted by programs or who share important demographic, social and economic characteristics with individuals who are most likely to be out of care.

COMMUNITY-BASED ORGANIZATIONS (CBOs)

Though some CBOs offer primary medical care and legal services, many do not. They do, however, often provide vital services that can affect how individuals are linked or retained in care and may engage in public policy and advocacy activities to protect and promote the well-being of people living with HIV. One advantage to seeking input from CBO representatives is that they may be particularly sensitive to the ongoing unmet needs among their constituents and may have greater understanding of the stakes involved in launching care linkage and retention services based on surveillance and other data.

Both focus groups and surveys may be employed with CBO representatives, though

focus groups are likely superior, particularly for planning purposes. Moreover, participants at the Think Tank recommended providing both context and questions to CBO representatives prior to a focus group or survey so that input from constituents and associates may be gathered. When program plans enter the final phase, DPHs may also make time for public commentary to be solicited.

HIV CARE PROVIDERS

HIV health care providers have a fundamental charge to preserve the health and well-being of the people they care for. For this reason, they can and should be active partners in efforts designed to improve HIV care linkage and retention, regardless of the method employed, but especially for programs where clinicians will be called upon to engage or re-engage their patients in health care. Additionally, clinicians can often be vital sources of information on the status of their patients. As such, surveillance officials can potentially strengthen the quality of their data by working collaboratively with clinicians.

Health departments may utilize a number of methods for soliciting feedback from clinicians. Focus groups may be particularly useful during the planning phase of programs though direct one-on-one interviews and surveys may also be employed, especially when evaluating the success of programs.

LEGAL AND ETHICAL EXPERTS

HIV has been and continues to be an exceptional disease when it comes to concerns over privacy of medical information. Early in the epidemic people with HIV were put at risk of not only their housing and employment should their HIV status become known, but also their physical safety. Also, prejudice and discrimination on the part of friends and family members are other risks that may occur with the breach of privacy. Sadly, there remain significant risks even today for people with HIV from inadvertent disclosure of HIV status to persons other than the person a program is seeking to engage or re-engage in care. Thus, specific privacy laws have been passed over the past 30 years to protect against these types of harms.

Moreover, not all states have the same statutes in place to define how HIV data may be used. This has led to a patchwork of different responses to those laws on a national basis. Legal experts are, therefore, necessary to ensure that proposed activities are consistent with laws currently in place or to propose changes in legislation that would be needed in order to proceed with certain activities.

In recent years there have been arguments about the need for a continued exceptional status for HIV privacy over and above other communicable or chronic diseases. This tension is made especially poignant given the potential for active uses of collected data at the present time to be used directly to promote the health of those who are out of care.

Because of the potential for both benefit and harm, it is crucial that public health departments engage legal experts, privacy advocates and ethicists to ensure that minimal harms are introduced.

INTERNAL STAKEHOLDERS WITHIN HEALTH DEPARTMENTS AND INFORMATION TECHNOLOGY EXPERTS

Care linkage and retention efforts can be costly and consume significant staff resources to properly implement them. Moreover, there may be different philosophies among health department staff members about when, how and whether private medical data may be used for anything other than passive surveillance of the HIV epidemic. Internal stakeholders may be particularly helpful in identifying potential practical and logistical obstacles to the implementation of various efforts. For these reasons, internal stakeholders should be consulted at the most formative point in developing new programs as well as in the evaluation of programs post-launch.

Information technology (IT) experts, both those working internally for health departments as well as outside consultants, are also highly recommended during the planning phase to assess the best methods for generating accurate “out-of-care” data and are absolutely vital in developing the architecture for programs that employ electronic sharing of collected data with private health care providers.

Participants recommended direct discussion and consultation, both in groups and individually, to solicit feedback from internal stakeholders and IT experts.

FUNDERS AND INSURERS

Certain activities would benefit from contact with key funders, insurers and government agencies. These would include AIDS Drug Assistance Program coordinators, officials from HRSA and the CDC, Ryan White Directors, state Medicaid officials and officials from the Center for Medicare and Medicaid Services (CMS).

ADDITIONAL RECOMMENDATIONS FOR HEALTH DEPARTMENTS

The majority of the recommendations made by the Think Tank participants for state and local health departments have already been covered by addressing policies and procedures and meaningful stakeholder engagement. Several further recommendations were made, however.

The first recommendation was to challenge assumptions that an activity that works well in one jurisdiction will necessarily have the same success in another. Both internal (within the DPH) and external factors can profoundly influence program design and execution. As well, the social and demographic factors of people living with HIV who are most likely to be out of care may differ from one location to another and these demand individualized approaches.

Another recommendation, which on its surface may seem obvious, is for health departments to do at least something about care linkage and retention, and not to bury their heads in the sand when confronted with these important challenges. While there may be difficult obstacles to overcome, these should not be excuses for inaction.

One thing that is also obvious from the previous sections is the need not to act unilaterally or to cling rigidly to conceptions that are held before engaging stakeholders. Think Tank

participants urged health departments to keep an open mind throughout the stakeholder engagement process.

There was a strong recommendation for local jurisdictions to explore using a peer navigator model for care linkage and retention—whether or not surveillance data are used. Think Tank participants recognized, however, that while this model has great promise, there are not yet high quality data on its efficacy nor are there significant funding streams available for these types of programs at the present time.

Recommendations for Advocacy Efforts

A larger discussion also took place that focused as much on what community advocates should do as what health departments should consider. Some of the recommendations are about harmonizing and consolidating efforts on data use and integrity, ensuring that states have the tools they need to at least track care linkage and retention and the need to seriously address HIV criminalization. Following are the recommendations and their rationale:

- Advocates and other stakeholders should harmonize the work of the Institutes of Medicine, Health and Human Services (HHS), CDC and various advocacy groups who are working on issues related to data integrity, core indicators for defining linkage and retention in care, and uses of multiple data sources, both public and private. This was seen to be a high priority issue as data integrity and completeness will be paramount not only for active uses of data described in this report, but also fundamentally to track how well people are being linked and retained in care more generally. Such data could also be used to issue report cards on care linkage and retention down to the local level, though some of the participants cautioned against using care linkage and data too punitively.
- Advocates should work with legal advocacy organizations and local advocates to consider legislation that would mandate reporting of CD4 counts and viral loads in every state. Moreover, community and legal stakeholders should review laws on data privacy to ensure a proper balance between privacy concerns and the ability to use data more actively to promote health among people living with HIV.
- Advocates should also work, however, to ensure that legislation is passed in every state to severely curtail how collected surveillance data may be used to aid in HIV-related prosecutions and be limited perhaps to cases where HIV transmission occurred.
- Advocates and public health departments should partner to introduce legislation to ensure proper penalties outlined in state law in cases where privacy breaches regarding client-level data occur.
- Public health officials and HIV advocates should engage in discussions about the adoptions of electronic medical records, by both private and public institutions, to ensure that the appropriate data are collected and that data sharing is not technologically impeded.

- Advocates should work to ensure that Ryan White funding continues and that explicit funding for care linkage and retention programs be considered.
 - Advocates and public health officials should engage in efforts to explore how the types of programs considered in this report could be tailored for cities, counties and states in the South East of the United States and in areas with significant rural epidemics as these have among the highest HIV incidence rates at the present time.
 - Recognizing that care linkage and retention are frequently associated with the offer of antiretroviral therapy, Think Tank participants recommended that medical boards and associations expand their efforts to ensure that HIV care is offered consistent with federal DHHS treatment guidelines.
-

Consensus Statement

Finally, Think Tank participants were asked to consider whether it would be possible for all present to agree on a simple consensus statement regarding the subject under question: Are more active uses of surveillance and other data acceptable for the purposes of linking and retaining HIV-positive individuals in care?

A strenuous discussion followed, which, in short, amounted to community advocates wanting to ensure that a consensus statement would be interpreted through the lens of other recommendations that had already been made to minimize harms and to ensure full stakeholder engagement.

During the discussion, two notable trends emerged. First, that public health officials present reaffirmed their dedication to meaningful stakeholder engagement. Second, that several community advocates arrived at the Think Tank fundamentally opposed to using surveillance data in a more active fashion, but that they had been convinced that the potential for benefits was significant.

With the safeguards enumerated above in place, local and state jurisdictions should begin reaching out to the community and other stakeholders to consider activities of this sort. The advocates stressed that the use of surveillance data was not the sole means for improv-

ing care linkage and retention, and that other types of efforts are either already in place or being planned that would not rely on this type of data. Nevertheless, they felt that the types of programs going on in Washington, D.C., Louisiana and King County, Washington were promising enough that other jurisdictions should explore similar efforts.

In the end, and after multiple rounds of suggested wording changes, AIDS service organizations, community-based organizations, academics, health departments and other non-federal agency stakeholders attending the meeting unanimously agreed to the following consensus statement:

“The benefits [to more active uses of collected data] potentially outweigh the risks so that we encourage local jurisdictions to actively engage stakeholders in considering the use of surveillance data along with other tools to systematically increase access to care, ensure better linkages to services, and improve retention in care.”

Conclusion

As stated many times at the Think Tank, the best of public health policy and practice is a true partnership between health officials and the community whose lives and health those officials are seeking to improve. The consensus statement reached by the participants is a symbol for what can be achieved when everyone works together with a common goal.

The efforts described that are taking place in Washington, D.C., Louisiana and King County, Washington exemplify the types of programs that may be employed to improve HIV care linkage and retention. They are not, however, the only locations that have launched such programs or that are planning to do so. It is Project Inform's sincere wish that public health officials in these additional jurisdictions have employed the types of policies and procedures outlined in this report and that meaningful stakeholder engagement has occurred or will occur if programs have yet to be launched.

In the event that such stakeholder engagement has not occurred, or not to the degree outlined in this report, the community can and should insist that such efforts be undertaken, not merely to shape or reshape programs, but also to provide constant and ongoing evaluation and quality assurance.

No single action is going to solve the care linkage and retention failures that occur among thousands of people in the United States. Implementation of the Affordable Care Act will hopefully extend health care to thousands of uninsured HIV-positive individuals and expand the menu of health care services available.

Implementation is likely to have great challenges, however, and is not of itself a solution to the many factors that lead people to fall out of care.

Likewise, the types of programs described should also not be seen as a sole solution to care linkage and retention programs. Their promise, as previously described, will rely heavily on the ability of health care providers and social service providers to adequately address the factors that caused someone to fall out of care in the first place.

That said, the early signs of success of these programs are encouraging and given the continued magnitude of the epidemic in the United States such success is urgently needed.

The value of a tool depends greatly on the intent and the skill with which it is being used. The tools described in this report will similarly depend on the intent and skill with which they are employed. Project Inform hopes that the recommendations outlined here help to ensure that health departments, in true partnership with the community, are better equipped and able to achieve the end goal, to ensure that people living with HIV have access to and remain engaged with high quality health care.

Think Tank Participants

Liz Brosnan,
Christie's Place

Natalie Cramer,
*National Alliance of State and
Territorial AIDS Directors*

Jeffrey Crowley,
*O'Neill Institute,
Georgetown University*

Moupali Das,
*University of California
San Francisco*

Julie Dombrowski,
*King Country Department
of Public Health*

Erica Dunbar,
*Centers for Disease Control
and Prevention*

David Evans,
Project Inform

Ann Fisher,
AIDS Legal Council of Chicago

Jane Herwehe,
*Louisiana Statue University
Health System*

Ernest Hopkins,
San Francisco AIDS Foundation

Charles King,
Housing Works

Matthew LeSieur,
Village Care

Kali Lindsay,
National Minority AIDS Council

James Loduca,
San Francisco AIDS Foundation

Hernan Luduena-Segre,
San Francisco General Hospital

Faye Malitz,
*Health Resources and
Services Administration*

Marsha Martin,
UCHAPS

Leisha McKinley-Beach,
Black AIDS Institute

Daniel Montoya,
National Minority AIDS Council

Michael Mugavero,
*University of Alabama,
Birmingham*

Courtney Mulhern-Pearson,
San Francisco AIDS Foundation

David Munar,
AIDS Foundation Chicago

Maura Riordan,
AIDS United

Susan Scheer,
*San Francisco Department of
Public Health*

Walt Senterfitt,
HIV Prevention Justice Alliance

Elizabeth Shepard,
*Louisiana Department of Health
and Hospitals, Office of Public
Health, STD/HIV Program*

Patricia Sweeney,
*Centers for Disease Control and
Prevention*

Tyler Termeer,
Ohio AIDS Coalition

Dana Van Gorder,
Project Inform

Tiffany West,
*Washington, D.C. Department
of Public Health*

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