Published in final edited form as:

J Acquir Immune Defic Syndr. 2015 May 1; 69(0 1): S31–S36. doi:10.1097/QAI.0000000000000573.

Acceptance of the Use of HIV Surveillance Data for Care Engagement: National and Local Community Perspectives

David Evans[1], **Dana Van Gorder**[1], **Stephen F. Morin, PhD**[2], **Wayne T. Steward, PhD, MPH**[2], **Stuart Gaffney**[2], and **Edwin D. Charlebois, MPH, PhD**[2]

David Evans: devans@projectinform.org; Dana Van Gorder: dvangorder@projectinform.org; Stephen F. Morin: Steve.Morin@ucsf.edu; Wayne T. Steward: Wayne.Steward@ucsf.edu; Stuart Gaffney: Stuart.Gaffney@ucsf.edu

[1]Project Inform, San Francisco, CA

[2]Center for AIDS Prevention Studies, University of California, San Francisco, CA

Abstract

Background—Use of surveillance data including laboratory results (e.g. CD4 and HIV RNA) by public health departments to facilitate linkage, retention, and re-engagement of HIV-infected individuals in health care is on the rise. This is part of the goal of increasing the proportion of infected persons achieving virologic suppression. However, this use of surveillance data is not without controversy, particularly among some providers and people living with HIV.

Methods—We conducted informal discussions with key stakeholders and a literature search, and held a national think tank in November 2012, bringing together 31 representatives of the federal government, county and state officials, health care providers, and community-based organizations. A follow-up community consultation specific to San Francisco was held January 24, 2014, with 10 participants. Notes from these activities were used as data for this analysis.

Results—The think tank identified three strategies utilizing HIV surveillance data to aid in care engagement: 1) provider-mediated – where health department staff work with the provider of record on re-engagement, 2) electronic linkages between surveillance databases and medical records databases, and 3) direct outreach – where trained health department staff reach out to persons out of care. Participants also developed recommendations for minimizing harm, guidance on meaningful stakeholder involvement, and a consensus statement in support of the use of HIV surveillance data in care engagement.

Conclusions—Acceptance of the use of surveillance data for HIV care linkage, retention, and re-engagement is achievable, particularly if stakeholders have been engaged in the design, conduct, and evaluation of programs.

Keywords

HIV Surveillance; Engagement in Care; Community Acceptance; Community Consultation; Continuum of HIV Care

---

Corresponding Author: Edwin Charlebois, 550 16th St., 3rd Floor, UCSF Mail Code 0886, San Francisco, CA. 94158, Edwin.Charlebois@ucsf.edu.

Conflicts of Interest: None of the authors has any conflict of interest to declare.

Introduction

Infectious disease surveillance is a practice that is over a century old[1]. Active uses of collected diagnosis data have included identifying individuals to be quarantined, tracking those exposed by a particular patient, and taking steps to link individuals to care or seek them out if they are lost to care. These efforts have predominantly been utilized with communicable diseases such as tuberculosis, and sexually transmitted infections such as syphilis and gonorrhea. It is only recently that public health officials have considered employing surveillance methods to the linkage and retention of HIV-infected individuals[2]. However, there is concern with this approach due to historically heightened sensitivities to, and consequences of, breaches of confidentiality, discrimination and interference between provider and patient[3].

In 2005 the New York City health department proposed implementing mandatory lab reporting of HIV viral load and drug resistance results to the public health department. This proposal was met with significant community controversy. Providers feared it would be intrusive, and community activists believed it was an overreach by the health department that would violate privacy standards around HIV that had been in place for many years. Indeed, the department had predicted that its proposal would be met with resistance. According to a representative from the city's health department, New York City has begun using disease intervention specialists to reach out to those that the public health department identifies as being out of care using surveillance data. This again raises the important issues of community acceptance of this approach.

Recently, considerable interest has focused on the HIV continuum of care which includes linkage to HIV care for HIV-infected persons and the proportion of individuals with HIV virologic suppression[4,5]. Estimates indicated that among the nearly 1.2 million people infected with HIV, only 30 percent are retained in care and have full viral suppression. Aside from the detrimental effects of unsuppressed virus for the individual living with HIV, recent research indicates that viral suppression reduces the risk of transmission in serodiscordant couples by at least 96 percent[6,7]. Combined with federal recommendations to treat people living with HIV regardless of CD4 count[8], the realization that treatment works to prevent HIV transmission offers new urgency to ensure that individuals are linked to care, retained, and virologically suppressed. This is consistent with the goals of the National HIV/AIDS Strategy for the United States[9,10] and the US HIV Care Continuum Initiative[8].

Since 2010, several programs in the United States have shown promise in this regard. In Washington, D.C. the department of public health regularly surveys laboratory data and, upon determining that a patient is out of care, notifies the health care provider of record[11]. In King County, Washington, the health department conducts a similar survey of data[12]. When a person is adjudicated as being out of care, the department first contacts the provider of record, and then with the provider's permission, seeks out the patient to reengage him or her in care. In this King County program, the public health department successfully contacted 219 people without a known viral load in the previous 12-months.

The Louisiana State University (LSU) health care system and the Louisiana public health department developed another approach for linkage to care using electronic information exchanges[13]. In that program the medical records database at LSU is electronically linked to the state HIV surveillance database. If a person judged out of care is seen by a provider in a participating hospital or clinic within the LSU system, a prompt in the medical record is generated to advise the clinician to engage or reengage the patient into HIV care. While these programs can be time, labor and resource intensive, they are producing results. In Louisiana, 488 alerts identified 345 HIV-infected out of care patients. Of those identified, 82% had at least one CD4 or HIV viral load test over the study follow-up period.

Given both the promise and controversy over these methods, Project Inform, a national HIV treatment advocacy and information organization, in consultation with investigators at the UCSF Center for AIDS Prevention Studies, sought to bring together a diverse group of stakeholders to discuss programs already in operation, methods to ensure the proper conduct of these programs if they are implemented elsewhere, and ways to ensure that key stakeholders are meaningfully engaged in program planning, implementation and evaluation.

The goal of the think tank was to develop a set of guidelines for public health departments on meaningful stakeholder engagement, recommendations for practices that could maximize success and minimize harm to HIV-positive persons – by inadvertent disclosure and confidentiality breaches or by increasing stigma – and to reach a consensus on the use of collected laboratory data for HIV care linkage and reengagement. Following the national think tank, a local consultation consistent with the recommendations from the think tank was undertaken in San Francisco to assess the acceptability of the use of HIV surveillance data for care engagement in a local jurisdiction.

Methods

In September 2012, Project Inform began informal discussions with critical stakeholders across the nation about how surveillance data including collected laboratory information were being employed for HIV care linkage and reengagement. After reviewing the available literature, themes explored included how HIV surveillance data were being used actively in particular jurisdictions, the degree of stakeholder engagement that took place in the design of these programs, the obstacles and challenges that were confronted, and how individuals felt personally and professionally about using surveillance data in this way.

From these discussions, Project Inform selected 31 diverse stakeholders for further exploration and consensus building. These included two individuals from the CDC, the former Director of the White House Office of National AIDS Policy, an official from the Health Services Resource Administration (HRSA), six public health officials, two treating physicians, a legal expert, university-based HIV researchers, and 16 community representatives including persons living with HIV.

Project Inform included community representatives to more directly represent the interests of people living with HIV. Some of these representatives are HIV-infected, and most had worked in HIV advocacy for many years and had a wealth of diverse experience.

In preparation for the think tank, a literature review was conducted, searching PubMed and Google Scholar with various combinations of the terms “HIV,” “surveillance,” “laboratory,” “healthcare,” and “retention.” From the literature review and previous discussion with stakeholders a briefing document was prepared on the use of collected laboratory data from a historical perspective, concerns regarding privacy and intrusion into standard HIV care, legal issues, examples of existing programs, and a set of key questions that would be used during the think tank. Individuals invited to the think tank on this issue were provided with the briefing document in advance of the meeting.

National Think Tank

The design of the think tank alternated between large group discussion and small break-out groups with report backs. Topics of discussion included stakeholder engagement, policies to guide the use of surveillance and other health data, practices to avoid, and steps forward.

The think tank participants were asked to engage in six separate discussions. Those six discussions included the following:

- Defining policies and procedures for each type of activity that would minimize risks of confidentiality breaches and stigma, as well as enhance benefits;
- Defining stakeholders who should be consulted during the planning and implementation of activities, as well as describing what meaningful engagement would look like;
- Identifying how local jurisdictions should respond to the need for innovative care linkage and retention activities;
- Identifying actions and priorities for advocates and others to move these issues forward on a national level;
- Developing and voting on a consensus statement regarding the use of HIV surveillance data and other data for care linkage and retention; and
- Defining issues for further follow-up and exploration.

In addition, think tank participants were challenged to enumerate the potential risks and benefits of each type of approach to finding those out of care.

Full group and sub-group discussions were not audio recorded and directly transcribed. Facilitators took notes of emerging themes and recorded agreed-upon consensus statements.

San Francisco Local Community Consultation

A follow-up local consultation was held in San Francisco on January 24, 2014. This consultation built off of the earlier Think Tank and covered similar themes, but specific to the context of the epidemic in San Francisco and the local response. As with the earlier think tank, participants were asked to comment on local programs of the Department of Public Health, including a care linkage program called LINCS, which utilizes disease intervention specialists (DIS) to ensure timely HIV care linkage following a diagnosis, and an earlier pilot program.

As with the think tank, discussions were not audio recorded or directly transcribed. Facilitators took notes of emerging themes and recorded agreed upon consensus statements.

Results

Three different strategies for using HIV surveillance data to enhance engagement in care were identified in the think tank discussions. The first strategy was provider-mediated outreach. In this strategy, HIV care status is defined by interactions between the public health department and provider of record. The ultimate responsibility for reaching out to out-of-care patients is the provider's. The second strategy explored was electronic health information exchanges, where public health data are electronically linked to medical records databases at health care institutions, thereby prompting clinicians to discuss HIV and care status with patients the system identifies as out-of-care. The third strategy was direct outreach to patients by disease intervention specialists employed by the public health department. There was universal agreement that each of the three strategies had the potential to improve the health and well-being of people living with HIV and to reduce HIV transmission, but that each presented unique challenges and the potential for harm if not done well.

Provider-Mediated Outreach

Of the three strategies, participants believed provider-mediated outreach had the least potential for people living with HIV to feel stigmatized about their status, given that relationships with health care providers have already been established. The issue of cost to the public health system arose during the discussion on the potential benefits and disadvantages of provider-mediated outreach, with participants pointing out that this approach could be among the least costly to public health departments, but most costly to providers. In systems where Ryan White funds are the primary source for medical care, ancillary service costs would be borne by the program. Lastly, it was noted that direct contact between the public health department and providers would likely result in improved data integrity.

One of the primary disadvantages of the provider-mediated outreach is that it does not address people who were never linked to HIV care in the first place. Also, busy clinics and HIV practices may have limited capacity for follow-up with patients who have fallen out of care. Lastly, but on a related note, some risk factors for being out of care, such as ongoing substance use or insecure housing, are difficult to solve and beyond the scope of the individual provider; simply reaching out to the health care provider would not address these problems.

Electronic Health Information Exchanges

Electronic health information exchanges are systems in which HIV surveillance data is interfaced with electronic medical record data producing information on out-of-care individuals and inform care providers of patient care status at the point of contact. One advantage of electronic exchanges over provider-mediated outreach is that these health information exchanges can find those who were never linked to HIV care in addition to those who are disengaged. Further, the approach takes advantage of missed opportunities for care linkage and reengagement within the health care system, and might reduce disparities in health care by broadening opportunity for care linkage and retention to multiple provider types not necessarily attached to HIV stigma such as emergency department providers.

One disadvantage to the electronic health information exchange strategy is its high cost, particularly in the start-up phase, and intensive technological capacity required by both public health departments and providers. The system in Louisiana worked because a vast majority of people living with HIV receive care from one large interconnected health care system with a shared medical records database. This is not the case in most jurisdictions with substantial HIV prevalence.

Another concern is that this approach relies heavily on providers with little to no expertise in HIV care or experience with appropriately linking or reengaging those out of HIV care. There is also the possibility that 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. Louisiana officials indicate that this has not been the case, and stated that the most common response is one of appreciation.

Direct Outreach to Patients

Of the three strategies explored during the think tank, direct outreach by the public health department to individuals living with HIV who are out of care engendered the most concern, particularly among community advocates. Nevertheless, all of the participants agreed that there could potentially be benefits to this approach, particularly if public health departments were to use peers or persons trained in patient navigation to conduct outreach. Anecdotal evidence from King County indicates that the open HIV status of the disease intervention worker (an HIV-infected peer) was a factor in getting some patients back into care. Moreover, the participants pointed to other types of HIV care linkage, navigation and adherence support models that have successfully utilized peers. With this strategy, health department personnel to be involved require additional training in patient navigation and other skills that are normally outside of the usual public health DIS officer activities.

As with the electronic exchanges, participants indicated that this strategy would allow departments to find those who were never linked to care in addition to those who fell out of care. In addition, if combined with provider-mediated outreach, it could result in substantial improvements in data integrity and completeness. It enhances the potential of departments to locate some of the hardest to reach patients and could allow outreach workers to immediately address some of the primary reasons that people are out of care, which includes a number of issues that traditionally have fallen under social work such as housing, substance abuse, and mental health treatment.

Policies and Procedures

The most frequently cited concern about policies and procedures was that “one size does not fit all.” In other words, whatever strategies 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. They may not be viewed favorably in areas where there have been difficult or minimal relations between stakeholders or where issues like HIV-related criminalization 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 such sources as Ryan White HIV/AIDS Program data, Medicaid and Medicare databases, and AIDS Drug Assistance Program data.

Reducing Harms and Maximizing Benefits

There were several recommendations on practices for health departments to maximize benefits and minimize harms regardless of the approach being used. Of prime importance was a definition of "out of care" that is consistent with national standards set by the Institute of Medicine (IOM)[14]. Additionally, participants noted data integrity and completeness is vital. Though active uses of surveillance data may also allow a department to improve their data, it can be quite resource-intensive and costly to proceed before minimum standards can be achieved. Lastly, participants urged that departments proceed in a fully transparent manner in the planning, execution, and evaluation of new programs.

Meaningful Stakeholder Engagement

Think tank participants stressed that 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 needed changes identified during the stakeholder engagement process.

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.

Lastly, participants recommended that multiple types of stakeholders should be consulted. These include people living with HIV, especially those who have had periods out of care, non-profit advocacy organizations, HIV care providers, legal experts, ethicists, and internal staff at departments of public health.

Consensus Statement

Finally, think tank participants were asked to consider a simple consensus statement concerning the question: *Are more active uses of surveillance and other data acceptable for the purposes of linking and retaining HIV-positive individuals in care?*

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

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."

San Francisco Local Community Consultation

Following the format and recommendations of the national think tank, local San Francisco stakeholders received a briefing from the local health department on current and planned uses of surveillance data. Based on this briefing, the stakeholders discussed the ethical dimensions of utilizing disease intervention specialists from the local public health department to conduct care linkage and reengagement activities. Responses to this approach by community-based advocates ranged from enthusiastic to extremely cautious. Again, this approach received broader support if conducted with particular care to the privacy needs of those living with HIV. Participants acknowledged that the anticipated consequences of reduced HIV testing, which was predicted when mandatory names reporting from those testing positive for HIV was implemented, did not occur.

The group as a whole agreed that these kinds of programs are best built from a legal, ethical and practical perspective when they are true partnerships between public health and community-based organizations and that they must respect people with HIV's autonomy about whether or not to be engaged in care and not be overly coercive. If a given person has a bad experience with being contacted by public health, they could be lost to care for a long time.

The department of public health acknowledged that their pilot program to locate those who had fallen out of care required significant resources. However, the program was able to find a substantial percentage of persons who actually were in care, moved, or who were lost to follow-up. Lastly, public health officials noted that staff-intensive programs such as these are often the first to be cut during times of budget shortfalls.

Discussion

In both the national and local consultations, there was universal concern about the significant gaps in the HIV care cascade and a shared sense that in order to improve the health outcomes of HIV-infected individuals in the United States, it would be necessary to consider different strategies than had been taken in the past—even those considered controversial. Overall the benefits outweigh the risks for the use of HIV surveillance data to improve linkage to care, retention, and re-engagement of HIV-infected persons.

Many of the most vulnerable and underserved people with HIV would likely be those with the greatest concerns about the negative effects that could result from breaches of medical privacy, including lost housing or employment, damaged relationships, stigma, and violence. While this group could suffer the most harm from adoption of surveillance-based linkage programs, it was also acknowledged that it could also have the most to gain from well-designed and trustworthy linkage and retention programs.

Public health departments, through their mandate to protect and improve the health of the public, have the authority to contact individuals without prior consent. This is commonly done in contact tracing and outbreak investigation, and rarely done in cases of involuntary quarantine for tuberculosis and more recently for potential Ebola virus exposure. However, in the context of HIV public health, having the authority to make such contacts informed by surveillance data and doing so without prior community support has significant potential to undermine community support. Thus, processes like the national think tank and the local community consultations are a key element in maintaining public trust and increasing acceptability of these proposed methods for linkage, retention and re-engagement in care[15,16].

Various requirements for surveillance of HIV-infected people, including the uniform adoption of name-based reporting, were initially met with predictions of harmful consequences that have not materialized to any significant degree. Therefore, programs that conduct direct outreach to HIV-infected people using surveillance data, if carefully operated, should not create the problematic breaches of privacy that have engendered opposition to them.

CDC and HRSA funding and technical assistance will be required to make it possible to support the development of effective programs. In fact, CDC in its effective interventions website Data to Care section[17] provides guidance to health departments on the use of HIV surveillance data to support improvements in the HIV care continuum that aligns well with the strategies identified in this project. Importantly, our findings speak to the national and local acceptability of the strategies contained with the CDC's evolving guidance, in particular the CDC guidance outlining proactive community engagement methods to promote community acceptance, a message echoed in our findings.

The question of whether government should use intensely personal data to support engagement in healthcare for what remains a stigmatized disease comes at a time when concerns about the use of personal information are being raised in society as a whole. Since the think tank held in November of 2012, these concerns have only increased as a result of breaches of sensitive personal and financial information both by government and private corporations.

Concerns of whether it is ethical to subject patients to potential breaches of medical privacy with their attendant potential harms remain. While the possibility of harm exists, specific steps to prevent it can be incorporated into program design. Moreover, given the opportunity to improve a patient's HIV-health outcomes and reduce HIV transmission, it would be unfortunate to not use a carefully designed surveillance based linkage program to link and retain persons in care and treatment as part of responding to the many challenges posed by the continuing HIV epidemic in the United States.

Acknowledgments

The authors wish to thank the participants in the National Roundtable and the local consultation for their time and perspectives: Natalie Cramer, Jeffrey S. Crowley, MPH, Moupali Das, MD MPH, Julie Dombrowski, MD MPH, Erica Dunbar, MPH, Ann Fisher, Jane Herwehe, MPH, Ernest Hopkins, Charles King, Matthew LeSieur, MS, Kali Lindsay, James Loduca, Hernan Luduena-Segre, LCSW, Faye Malitz, MS, Marsha Martin, MS DSW, Leisha McKinley-Beach, Daniel Montoya, Michael Mugavero, MD MHSc, Courtney Mulhern-Pearson, MPH, David Munar, Maura Riordan, Susan Scheer, PhD MPH, Walt Senterfit, PhD MPH, Elizabeth Shepard, Patricia Sweeney, JD MPH RN, Tyler Termeer, MS, Tiffany West, MS MSPH, Bill Hirsh, JD, Michaela Hoffman, MPH, Lee Jewell, MA MFTI, Diane Jones, RN, Kyriell Noon, Tracy Packer, MPH, Mike Smith, MBA, Lori Thoemmes, LMFT, Lance Toma, MSW.

Sources of funding for the National Think Tank were provided to Project Inform by Bristol-Myers-Squibb, Gilead Sciences, Janssen Therapeutics, MAC AIDS Fund, and the San Francisco Foundation. The local community consultation was supported by a supplement (PI Charlebois) to the NIH-funded DC D-CFAR (Grant number 5P30A1087714 –PI Greenberg, and UCSF GVRI CFAR 5P30AI027763, PIs; Warner Greene and Paul Volberding, and the UCSF Center for AIDS Prevention Studies 5P30MH062246, PI: Stephen F. Morin).

References

1. Lee, Lisa M.; Teutsch, Steven M.; Thacker, Stephen B.; Louis, MES. Principles and Practice of Public Health Surveillance. 3rd. New York, New York: Oxford University Press Inc.; 2010.
2. Sweeney P, Gardner LI, Buchacz K, et al. Shifting the paradigm: using HIV surveillance data as a foundation for improving HIV care and preventing HIV infection. The Milbank quarterly. 2013; 91(3):558–603. [PubMed: 24028699]
3. Fairchild AL, Bayer R. HIV surveillance, public health, and clinical medicine--will the walls come tumbling down? The New England journal of medicine. 2011; 365(8):685–687. [PubMed: 21864165]
4. Gardner EM, McLees MP, Steiner JF, Del Rio C, Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. Clinical infectious diseases : an official publication of the Infectious Diseases Society of America. 2011; 52(6):793–800. [PubMed: 21367734]
5. Morin SF, Kelly JA, Charlebois ED, Remien RH, Rotheram-Borus MJ, Cleary PD. Responding to the National HIV/AIDS Strategy-setting the research agenda. Journal of acquired immune deficiency syndromes. 2011; 57(3):175–180. [PubMed: 21606844]
6. Cohen MS, McCauley M, Gamble TR. HIV treatment as prevention and HPTN 052. Current opinion in HIV and AIDS. 2012; 7(2):99–105. [PubMed: 22227585]
7. Bradley H, Hall HI, Wolitski RJ, et al. Vital Signs: HIV diagnosis, care, and treatment among persons living with HIV--United States, 2011. MMWR Morbidity and mortality weekly report. 2014; 63(47):1113–1117. [PubMed: 25426654]
8. Adolescents PoAGfAa. (DHHS) DoHaHS, ed. Bethesda, MD: Government of the United States; 2014. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents.
9. Policy WHOoNA. Policy WHOoNA, ed. Vol. 45. Wasington, DC: Governement of the United States; 2010. National HIV/AIDS Strategy for the United States.
10. Policy WHOoNA. Policy WHOoNA, ed. Vol. 23. Wasington, DC: Governement of the United States; 2013. Improving Outcomes; Accelerating Progress Along the HIV Care Continuum.
11. Washington, DC: Recapture Blitz; 2010. Ryan White Grantees. Available at http://nationalqualitycenter.org/download_resource.cfm?fileID=36822 [accessed March 17, 2014]
12. Dombrowski, JC.; Fleming, M.; Simoni, J.; Hughes, JP.; MR, G. Conference on Retroviruses and Opportunistic Infections. Vol. 2013. Atlanta, GA: Mar 3–6. 2013 Surveillance-based outreach to promote HIV care engagement and antiretroviral use: Results from the pilot phase of a health department intervention.

13. Herwehe J, Wilbright W, Abrams A, et al. Implementation of an innovative, integrated electronic medical record (EMR) and public health information exchange for HIV/AIDS. Journal of the American Medical Informatics Association : JAMIA. 2012; 19(3):448–452. [PubMed: 22037891]
14. Institute of Medicine. Monitoring HIV Care in the United States: Indicators and Data Systems. 2012.
15. Morin SF, Maiorana A, Koester KA, Sheon NM, Richards TA. Community consultation in HIV prevention research: a study of community advisory boards at 6 research sites. Journal of acquired immune deficiency syndromes. 2003; 33(4):513–520. [PubMed: 12869841]
16. Morin SF, Morfit S, Maiorana A, et al. Building community partnerships: case studies of Community Advisory Boards at research sites in Peru, Zimbabwe, and Thailand. Clinical trials. 2008; 5(2):147–156. [PubMed: 18375653]
17. CDC. [Accessed November 14th, 2014] Data to Care - Effective Interventions, HIV Prevention That Works. 2014. http://www.effectiveinterventions.org/en/HighImpactPrevention/PublicHealthStrategies/DatatoCare.aspx