

Shifting the Paradigm: Using HIV Surveillance Data as a Foundation for Improving HIV Care and Preventing HIV Infection

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Context: Reducing HIV incidence in the United States and improving health outcomes for people living with HIV hinge on improving access to highly effective treatment and overcoming barriers to continuous treatment. Using laboratory tests routinely reported for HIV surveillance to monitor individuals' receipt of HIV care and contacting them to facilitate optimal care could help achieve these objectives. Historically, surveillance-based public health intervention with individuals for HIV control has been controversial because of concerns that risks to privacy and autonomy could outweigh benefits. But with the availability of lifesaving, transmission-interrupting treatment for HIV infection, some health departments have begun surveillance-based outreach to facilitate HIV medical care.

Methods: Guided by ethics frameworks, we explored the ethical arguments for changing the uses of HIV surveillance data. To identify ethical, procedural, and strategic considerations, we reviewed the activities of health departments that are using HIV surveillance data to contact persons identified as needing assistance with initiating or returning to care.

Findings: Although privacy concerns surrounding the uses of HIV surveillance data still exist, there are ethical concerns associated with not using HIV

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surveillance to maximize the benefits from HIV medical care and treatment. Early efforts to use surveillance data to facilitate optimal HIV medical care illustrate how the ethical burdens may vary depending on the local context and the specifics of implementation. Health departments laid the foundation for these activities by engaging stakeholders to gain their trust in sharing sensitive information; establishing or strengthening legal, policy and governance infrastructure; and developing communication and follow-up protocols that protect privacy.

Conclusions: We describe a shift toward using HIV surveillance to facilitate optimal HIV care. Health departments should review the considerations outlined before implementing new uses of HIV surveillance data, and they should commit to an ongoing review of activities with the objective of balancing beneficence, respect for persons, and justice.

Keywords: HIV surveillance, HIV treatment, HIV prevention, ethical data use.

IN THIS ARTICLE, WE EXPLORE HOW RECENT ADVANCES IN HIV treatment and prevention are motivating the rethinking of the uses of HIV surveillance data. The arguments for this change, like those for the decision to implement AIDS surveillance in the mid-1980s and the evolution of HIV surveillance since then, are framed by conceptions of what constitutes public health surveillance and what uses of surveillance data are ethically appropriate.

Public health surveillance is the ongoing, systematic collection, analysis, and use of health-related data to prevent or control disease (Thacker 2010). In the United States, state and local health departments collect information from health care providers and laboratories that are required by state law or regulation to report diagnoses of notifiable diseases. An infectious disease case report generally describes the patient's demographics and clinical information establishing the diagnosis. Surveillance has provided the "who, what, when, and where" descriptions of patterns of infection and disease occurrence that have guided public health prevention and control measures at both the population and individual levels. Public health agencies have traditionally worked with practicing clinicians who report diagnoses for surveillance to implement infectious disease prevention and control interventions such as the following:

- Notifying infectious people of their diagnosis, treating them, or taking other measures to interrupt transmission.

- Interviewing index patients to identify other persons exposed to infection.
- Notifying contacts of their exposure (contact tracing) and diagnosing and treating infections among contacts or otherwise containing these infections.
- Assisting uninfected contacts with ongoing exposure to avoid infection (CDC 1995, 2008, 2010; WHO 2011).

Even though public health surveillance is the foundation for promoting public health, the surveillance itself—and some uses of surveillance data—risks infringing on privacy and individual liberty. Patient identifiers are attached to case reports, and laboratory data are reported to surveillance, but the patients' consent is not required. Governmental use of surveillance data to protect the population's health may conflict with individual interests because having a disease can be stigmatizing, and controlling the spread of infection may necessitate contact tracing—or other measures that infected persons may consider harmful or intrusive (Heilig and Sweeney 2010). Therefore, the adequacy of legal and other controls for protecting the privacy of health-related information and preventing discrimination and other harms is an important policy consideration underlying the collection and use (or nonuse) of surveillance data.

In the mid-1980s, attempts to mandate name-based reporting of AIDS diagnoses generated public debate about the tension between protecting the public's health and the privacy and rights of individuals (Fairchild, Bayer, and Colgrove 2007). Opponents of name-based AIDS surveillance, particularly gay men among whom HIV was taking the greatest toll, feared intrusion into their private lives and disclosure of stigmatizing information from surveillance reports. In a society intolerant of homosexuality, some feared that HIV might even be used to rationalize quarantine as a means of isolating and further disenfranchising homosexuals. In fact, in 1985, one group critical of the public health response to AIDS signaled to the California attorney general that it intended to advance such a proposal as a ballot proposition for the 1986 election (Bayer 1989, 137–69).

In the late 1980s, when national organizations of medical and public health professionals first suggested using HIV surveillance for public health intervention in connection with proposals for initiating name-based HIV reporting (Fairchild, Bayer, and Colgrove 2007, 183–84), there was no effective HIV treatment, and HIV/AIDS-related misconceptions and stigma were prevalent. The belief that the individual and

public benefits were not sufficient to balance the infringement on individual rights of HIV-infected persons guided the resulting retreat from traditional infectious disease control strategies like contact tracing. In some jurisdictions, HIV-affected communities supported the name-based reporting of HIV diagnoses for surveillance only if health departments promised not to use the information for public health interventions. Pressure from AIDS activists led to the implementation of unprecedented data security and confidentiality protections for the collection and management of HIV surveillance data, protections that continue to be required as a condition for federal funding of state and local health department surveillance programs (CDC 2011b; 2012b). Many states also enacted laws limiting the disclosure of HIV data (O'Connor and Matthews 2011). As a result, health departments have not widely used HIV surveillance data for disease control interventions with individuals, such as facilitating their access to medical care and treatment, an approach that has been used to control epidemics of other infectious diseases, for example, other sexually transmitted diseases and tuberculosis (CDC 2008; Fairchild and Bayer 2011; Fairchild, Bayer, and Colgrove 2007; Fairchild et al. 2007).

Before and since the adoption of name-based HIV surveillance, objections to using surveillance data for intervention with HIV-infected individuals have clashed with assertions that intervening to prevent and control disease is the primary purpose for collecting these data (Fairchild, Bayer, and Colgrove 2007). Here we examine how advances in both HIV treatment and surveillance have altered the risks and benefits of applying surveillance-based disease prevention and control strategies to HIV. We then describe health departments' shift toward using surveillance to guide follow-up contacts with HIV-positive individuals to facilitate HIV medical care, including antiretroviral treatment. Last we review the ethical arguments for this paradigm shift, using examples from ongoing work to illustrate the ethical, procedural, and strategic considerations.

Public Health Ethics Framework for the Uses of Surveillance Data

The ethical appropriateness of collecting and using public health surveillance data can be determined by applying three well-known principles that were first advanced to protect human subjects in

biomedical research: beneficence, respect for persons, and justice (Heilig and Sweeney 2010; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979). *Beneficence* requires that public health practitioners use HIV surveillance for a legitimate public health purpose (Kass 2001) while minimizing potential harms. *Respect for persons* conveys an obligation for health departments using HIV surveillance data to honor individuals' ability to make and act on their decisions as long as the decisions do not harm others. *Justice* demands that HIV surveillance be used to address disparities in access to health care and in the distribution of HIV morbidity and mortality. Although beneficence, respect for persons, and justice all must be considered to make an affirmative case for a public health intervention, each represents an obligation that must be balanced against the other two (Lee 2012). Childress and coauthors (2002) proposed five conditions to help balance these three principles and resolve conflicts among them: (1) *effectiveness*, (2) *proportionality* (benefits must outweigh the infringement), (3) *necessity* (any infringement must be necessary), (4) *least infringement* (only the least possible infringement is justified), and (5) *public justification* (transparency and accountability require a public explanation of infringement). In the case of a specific public health intervention like the use of surveillance to facilitate HIV care, assessing the presence or absence of these conditions is useful for determining whether the pursuit of the common good (beneficence, justice) justifies some infringement of individual liberty.

Revisiting Ethical Arguments

Historically, in the absence of effective treatment and given the prevailing HIV stigma, opponents of HIV surveillance-based disease control strategies believed that the individual and public benefits were not sufficient to justify the infringement on individual rights. Two factors are compelling a reconsideration of the ethical arguments against these strategies: (1) the strong evidence that antiretroviral treatment is lifesaving (Nakagawa et al. 2012; Palella et al. 1998; Walensky et al. 2006) and prevents the transmission of HIV infection (Cohen et al. 2011) and (2) the current deficiencies in linkage and retention in HIV medical care, which restrict the individual and public health benefits of antiretroviral treatment (Burns, Dieffenbach, and Vermund 2010;

CDC 2011d). The fact that the burdens of HIV morbidity and mortality and the benefits of HIV care, including antiretroviral treatment, are unequally distributed (Arnold et al. 2009; CDC 2012a; Harrison, Song, and Zhang 2010; Johnston et al. 2013; Losina et al. 2009; Millett et al. 2012) is prompting the reconsideration of using surveillance to support clinical intervention. Although the privacy concerns surrounding the uses of HIV surveillance data still exist, there are also ethical concerns associated with not using HIV surveillance to foster the individual and public benefits of HIV medical care and antiretroviral treatment.

In addition to the ethical arguments, there are practical arguments for reconsidering the uses of HIV surveillance information. The National HIV/AIDS Strategy, issued in 2010 by the U.S. Office of National AIDS Policy (Office of National AIDS Policy 2010), aims to maximize the survival and prevention benefits of continuous medical care started early in the course of infection (Buchacz et al. 2010; Hall et al. 2012; Hanna et al. 2012; Harrison, Song, and Zhang 2010; Kitahata et al. 2009; Losina et al. 2009; Marks et al. 2010; Walensky et al. 2006). However, recent data highlight the obstacles to achieving National HIV/AIDS Strategy objectives. According to these data, 80 percent of HIV-infected persons in the United States are diagnosed; 77 percent of persons who are diagnosed with and aware of their HIV infection are initially linked to care within three to four months of their diagnosis; and 51 percent of diagnosed persons living with HIV remain in care. Among all HIV-infected persons in the United States, including both diagnosed and undiagnosed, only an estimated 28 percent are virally suppressed (CDC 2011d), a therapeutic objective central to maximizing survival and preventing ongoing transmission.

Increasing the proportions of HIV-infected individuals diagnosed, linked to care, and retained in care are widely seen as critical steps toward reducing the current number of new infections occurring in the United States (Prejean et al. 2011) to a level presumably achievable through widespread antiretroviral treatment (Cohen et al. 2011). Public health agencies are accountable for working with medical care providers to meet this challenge, as well as for improving access to lifesaving treatment for those whom care systems have failed (IOM 2002, 32). Furthermore, surveillance-based intervention is a tested public health strategy for improving case-finding and treatment. Although public health agencies have both a duty and, in surveillance-based strategies, an effective means to respond to HIV, balancing beneficence and justice

with respect for privacy and individual rights remains essential to the ethical justification of HIV surveillance-based intervention.

Paradigm Shift

During the past decade, the HIV surveillance system has been evolving. Since 2008, all states have required reporting HIV-positive test results using a confidential name-based system. In addition, as of January 2013, thirty-six state health departments plus Puerto Rico, Guam, and the cities of Philadelphia and Washington, DC, mandate confidential, name-based reporting of all CD4 T-lymphocyte (CD4) and HIV viral load (VL) tests by laboratories to health departments' HIV surveillance units. Providers routinely order these tests to guide treatment (Panel on Antiretroviral Guidelines for Adults and Adolescents 2012). Public health agencies use these CD4 and VL tests reported to surveillance as indicators to track linkage to and retention in care (Dombrowski et al. 2012; Thompson et al. 2012).

The ability to track linkage to and retention in HIV care has given health departments a useful tool for focusing efforts to facilitate optimal care (Frieden et al. 2005). This capacity together with the well-recognized health benefits from HIV treatment, the growing potential for HIV prevention, and the momentum provided by the first U.S. National HIV/AIDS Strategy have prompted a paradigm shift from simply monitoring linkage and retention to monitoring as the basis for action (CDC 2011c; Fairchild and Bayer 2011). Some health departments are now using the reported CD4 and VL tests both to identify those needing, but not connected to, care and to activate follow-ups to engage or reengage them with the care system. Next, we present examples from this ongoing work, discuss their fit with the three ethical principles and Childress's five "justificatory conditions," and review procedural and strategic considerations for this use of HIV surveillance data.

Examples Illustrating Different Approaches

The following examples illustrate the use of HIV surveillance data to identify persons presumed to need HIV medical care. The examples

highlight different approaches to facilitating care, including making contact with persons living with HIV, assisting HIV medical care providers with making these contacts, and transferring elements of surveillance data to electronic medical records to alert providers to patients who have missed receiving HIV care. The examples are summarized in table 1.

Using HIV Surveillance to Make Contact with Persons Living with HIV

Example 1. In 2008, the New York City Department of Health and Mental Hygiene began to use reported HIV-related laboratory tests to identify and contact persons apparently not receiving care. In New York City, health department staff members who conduct HIV surveillance and outreach activities are integrated in the HIV Epidemiology and Field Services unit of the Bureau of HIV/AIDS Prevention and Control. Field services staff members conduct outreach activities, such as partner services and interventions to facilitate HIV care. Some of these field services staff members work from health department offices alongside surveillance staff. Additional field services staff are embedded in all the major comprehensive HIV treatment centers in New York City, which are not administered by the health department.

Authorized health department staff regularly review the surveillance records, including reported laboratory data, and identify persons who have been diagnosed with HIV who have had no CD4 or VL test results for at least nine months or who have a sustained high viral load and appear to have had no medical follow-up.

A key feature of the approach in New York City is the health department's close relationship with health care facilities, which is facilitated by the embedded health department staff in those facilities. This relationship permits access to medical records that are used by the department's field services staff to verify that persons identified from surveillance data are not receiving care at their original or other participating facility. Verification in medical records is a critical first step, because delays in reporting CD4 and VL tests to surveillance may cause a person who is receiving HIV medical care to appear to not be receiving care. If no evidence of an HIV care visit is found in the medical records of participating sites, field services staff initiate contact with the

TABLE 1
Examples of HIV Surveillance-Based Activities to Promote Linkage and Retention in HIV Medical Care

Location	Follow-Up Triggered by Records of	Type and Content of Follow-Up Contacts	Who Initiates Follow-Up?	Key Features
New York City	Health department	Letter, phone call, and/or home visit to offer persons diagnosed with HIV information about HIV, HIV prevention, and HIV medical care; ascertain their reasons for not receiving care; and offer assistance with linkage or reengagement in care.	Health department DIS ^a	Authorized staff regularly review surveillance records to identify HIV-diagnosed persons who have had no CD4 ^b or VL ^c test results for ≥ 9 months or who appear to lack medical follow-up of detectable VL. Assistance with connecting to care is offered through an expansion of the infrastructure supporting HIV partner services. Collaborations with providers were extended to include all major HIV care centers. Incremental structural, legal, and policy changes provided the necessary foundation.

Continued

TABLE 1—Continued

Location	Follow-Up Triggered by Records of	Type and Content of Follow-Up Contacts	Who Initiates Follow-Up?	Key Features
Seattle—King County, Washington	Health department	Phone call, then in-person interview to ascertain the primary reason for not receiving care and to provide guidance to resources for obtaining and remaining in care.	Health department; staff doing follow-up are trained as peer navigators.	Authorized staff review surveillance records to identify HIV-diagnosed persons with no CD4 or VL tests reported for ≥ 12 months or with a most recent CD4 count of < 500 mm ³ and a VL of > 500 copies/mL. Health department confirms “out of care” status with provider first before following up with individuals. Reengagement activities involve stipend for interview. Formative work included assessments of provider and patient acceptability and a pilot to assess feasibility and limitations of surveillance.

Continued

TABLE 1—Continued

Location	Follow-Up Triggered by Records of	Type and Content of Follow-Up Contacts	Who Initiates Follow-Up?	Key Features
Washington, DC	HIV medical care provider or clinic	Phone call to remind patients of the need for continuous care and to assist them in reengaging with their Ryan White care provider.	HIV care provider/clinic	Ryan White providers send a list of patients without a clinic visit in >6 months; the health department matches these lists to surveillance data and AIDS Drug Assistance Program databases to identify patients receiving care in another location. Ryan White-funded providers initiate a 90-day intensive effort to reengage those not receiving care elsewhere. Rules for sharing the minimum amount of information necessary are strict. No additional health department staff are hired; rather, the program relies on existing relationships with providers that have a fiscal relationship with the health department.

Continued

TABLE 1—Continued

Location	Follow-Up Triggered by Records of	Type and Content of Follow-Up Contacts	Who Initiates Follow-Up?	Key Features
Louisiana	Health department	During patient-initiated visit for any type of care in the system's emergency department or inpatient or outpatient settings. Providers receive a public health message that they then discuss with their patients to determine whether they are receiving HIV medical care, and if not, whether they want to receive HIV care. The providers may then take action, such as referring the patients for treatment or scheduling an appointment, discussing the importance of treatment with the patients, and assessing the patients' health and disease stage.	Medical care provider/clinic	Triggers a real-time point-of-service alert when an HIV-diagnosed person who has no reported CD4 or VL tests in > 12 months presents for any medical care visit in the participating health care system. This alert involves connecting information systems infrastructures of the public health department and the health care delivery system, creating an electronic medical record alert, and instituting a formal governance structure for ongoing evaluation. The formative work included ethical and legal reviews and assessments of provider and patient acceptability.

Notes: All programs are ongoing.

^aDIS = Disease intervention specialist

^bCD4 = CD4+ T lymphocyte

^cVL = viral load

patient by telephone, email, or visit, depending on the available contact information from public health or medical records or other sources. They make at least three contact attempts, approximately two weeks apart. Their relationship with the HIV care facilities helps field services staff to obtain appointments for clients with a medical care provider.

When field services staff contact individuals, the first step is to confirm their identity by comparing information they provide with the surveillance records. Only when they are sure of a person's identity do they ask whether he or she has seen a health care provider about HIV at the patient's last or usual health care facility. If not, the individual is asked whether he or she has transferred to another care facility. Based on the answer, field services staff may begin a specific discussion about HIV care and partner services. If the person is receptive, and depending on his or her needs, staff may provide information about HIV infection and how it spreads, as well as the benefits of care. They offer partner services and, if the person wants to obtain HIV care, offer to assist with linkage to a medical care provider (Udeagu et al. 2012). This assistance includes directing the client to the most appropriate or preferred clinic, making appointments and/or providing transportation to the appointment, and offering reimbursement for transportation after the appointment has been kept. If the person wishes to end the interaction, field services staff close the case and make no further contact attempts. If the person does not want to obtain care but allows the interaction to continue, field service staff explain the services available and the benefits of staying in touch, provide a brochure about HIV infection, and offer to call back two weeks later unless the person contacts them first, which he or she is encouraged to do.

In New York City, the use of CD4 and VL test results as a foundation for interventions was initially proposed in 2005, at a time when policy strictly limited the use of surveillance data for epidemiologic monitoring. The health department held many discussions on the appropriateness of using HIV surveillance data to support linkage to and retention in HIV care, disease management, and quality of care improvement. During the following years, data showing the value of HIV testing and linkage to care became increasingly compelling, and the proposed changes gained acceptance among key stakeholders. In 2006, the program's structure within the health department was changed to enhance field service operations, and in 2010, New York State modified

its HIV testing laws to require the expansion and routinization of HIV testing and linkage to care.

According to a recent evaluation of the field services program (Udeagu et al. 2012), from July 2008 to December 2010, 797 HIV-diagnosed persons were prioritized for outreach; 14 percent were never located. Of the remaining 689, 229 (33%) were receiving care in New York City; thirty (5%) had moved or were incarcerated; sixteen (2%) had died; and 414 (60%) were not receiving HIV care. When located, 79 percent of the 414 expressed a willingness to return to care and received clinic appointments; 72 percent were confirmed as having returned to care, according to CD4 or VL test results reported to surveillance.

Example 2. A similar project, the Not in Care Evaluation (NOTICE) Project, was conducted in King County, Washington State, after a state law in 2006 required the reporting of all CD4 and all VL values. The NOTICE Project expanded linkage to care assistance that had been offered since 2000 through population-based partner services triggered when an HIV diagnosis was reported to surveillance. During the project's first wave, staff investigated 240 cases diagnosed at least one year earlier and without CD4 and VL tests reported to surveillance in the past year, when no evidence could be found that the individual had moved, was in care, or had died. Results reported from 2007 through 2009 indicated that 184 (77%) were misclassified as not being in care, including five persons who had died, eighty-six who had relocated, and ninety-three who were receiving care in Seattle–King County. Reasons that the latter group did not have CD4 and VL tests reported to the surveillance system included receipt of care through participation in research (23%) and delayed compliance of laboratories and providers with reporting requirements (Buskin et al. 2011). The investigators noted that uncovering some incomplete reporting through this project led to improvements in the quality of surveillance data.

In 2009, the Department of Public Health in Seattle and King County began assessing the acceptability of expanding these services further, to encompass early relinkage assistance and add new eligibility criteria that would expand outreach services to promote retention in care. This assessment involved qualitative interviews with twenty HIV-diagnosed persons selected randomly from surveillance records; qualitative interviews with fifteen HIV care providers, including physicians and physicians' assistants; and a group meeting with Seattle-area HIV care providers (Dombrowski 2012b). According to the health department

staff making the assessment, HIV-diagnosed persons interviewed welcomed the program as another source of support in addition to their health care provider and as a way to ensure that no one “fell through the cracks” of the care system (J.C. Dombrowski, personal communication, December 21, 2012). Although they did not express privacy concerns on their own behalf, they acknowledged that some of their peers might have some. Providers expressed concerns about their patients’ reactions to being contacted and about interference with the provider-patient relationship, and not all supported extending contact to persons with $CD4 > 500$ cells/mm³. The plans for the program were adjusted to address this feedback and were discussed at subsequent meetings with large medical practices, case management organizations, and the leadership of the two local community advisory boards with representation of persons living with HIV (Dombrowski 2012b).

The Department of Public Health launched the expanded program in 2011. Surveillance staff review $CD4$ and VL tests reported to surveillance to identify HIV-diagnosed persons who have not had laboratory tests reported for at least twelve months or with a most recent $CD4$ count of <500 cells/mm³ and a VL of >500 copies/mL, signifying that they may not be receiving optimal care (Dombrowski 2012a). Disease intervention specialists—public health workers who conduct case investigations of HIV infection and other sexually transmitted infections—first confer with the provider about contacting the persons identified, thereby giving the provider the opportunity to opt out of follow-up on behalf of any patient. Contact is attempted only if the provider approves. The disease intervention specialists contact the patients identified through surveillance to determine whether they are indeed out of care and offer participation in an individual counseling intervention, help with medical appointments, and referrals for supportive services to overcome barriers to quality care.

The disease intervention specialists make the initial contact by phone and mention HIV only if the person sought is available to speak. During this contact, they assess the patient’s needs, offer assistance, if desired, with medical appointment scheduling and case management, and promote participation in a program to address barriers to care. This program, the Care and Antiretroviral Treatment Promotion Project (Dombrowski 2012b), offers a stipend for participation in a face-to-face interview. If the person contacted consents to an interview, it is scheduled for a later date, at which time the person is asked about his or her reasons for not

being in care. A plan for engaging in care is developed, and a summary of the interview and plan is given to the medical care provider and the clinic or community-based HIV medical case manager, if any, who most recently worked with the client. Participants in the program are contacted again one month after the interview or as the need arises, and additional referrals may be offered. These activities are supported by CDC demonstration project funding and by the HIV/AIDS Bureau of the Health Resources and Services Administration.

Using Surveillance Data to Assist HIV Medical Care Providers

Beginning in 2009, the District of Columbia Department of Health launched a recurrent, time-limited collaboration with providers of care financed by the Ryan White Program to reengage HIV-diagnosed persons who have not had a recent care visit. Ryan White providers send the health department a list of patients not seen in their clinics for more than six months. The department compares these lists with surveillance data and the database of the AIDS Drug Assistance Program, which provides medication assistance to low-income patients as part of the Ryan White Program. The providers are told whether the match indicates that individual patients are receiving care in another location. The medical care providers then start a ninety-day intensive effort to reengage those not in care elsewhere (District of Columbia 2011). Before piloting this program, the District of Columbia Department of Public Health worked with health care providers and community-based organizations on devising strategies to actively use HIV surveillance data and again to develop plans to scale it up. In presentations, project staff have emphasized that the key strategies were building relationships and partnerships focused on implementation, formalizing these through memoranda of understanding and applying both top-down and bottom-up approaches to problem solving (District of Columbia 2010; West 2011).

Using Surveillance Data to Alert Providers

In 2009, the Louisiana Office of Public Health began implementing the Louisiana Public Health Information Exchange Project (LaPHIE). Through this project, a real-time point-of-service alert is triggered when

an HIV-diagnosed person who has not received CD4 or VL monitoring in more than twelve months presents for any kind of medical care in the participating health care system. This alert capability was made possible by the integration of HIV surveillance information and the clinical information system of Louisiana's largest provider of inpatient and ambulatory HIV medical treatment, the Louisiana State University Health Care System, which is one of the country's largest public health care delivery systems (Louisiana State University 2012). The secure, bidirectional system for the exchange of data between statewide HIV surveillance and electronic medical records sends messages to providers accessing the records of identified individuals to encourage them to use the health care visit to discuss and deliver HIV care or to refer the patient to an HIV specialist. Providers document the actions taken on an electronic "intervention note" returned to the health department. The health department then uses this information to decide whether the individual should continue to be considered "out of care" (Herwehe et al. 2011).

The Louisiana Office of Public Health conducted an ethical review with the assistance of national experts before it implemented this information exchange. Other formative activities included a review of state legislation to survey the legal environment for sharing public health information, an assessment of physician and patient acceptability (Louisiana Office of Public Health 2012), solicitation of input from physicians and public health personnel to design the alerts, and engagement of stakeholders to build consensus and a commitment to protecting patients and public health (Herwehe et al. 2011). Louisiana is using a participatory approach with ongoing oversight by public health and health care delivery stakeholders to ensure that the surveillance data are being used as intended—to identify and assist HIV-diagnosed persons who are not receiving care—and that the program adheres to privacy and security standards (CDC 2011b).

Ethical Considerations

Considering these examples with respect to beneficence, respect for persons, and justice illustrates how the demands imposed by these principles can conflict. Public health beneficence entails promoting, protecting,

improving, and, when necessary, restoring the health of individuals, groups, or the entire population (Last 2007). In the examples, surveillance data are being used for a legitimate public health purpose: facilitating HIV care that improves the health of HIV-infected individuals and prevents transmission of infection, which benefits the larger population at risk of acquiring infection. But all these approaches entail some threat to beneficence, primarily from disclosing HIV status, which can expose people living with HIV to stigma, discrimination, or violence. The risk of harm historically is low from surveillance-based outreach activity with similar risks, that is, notifying partners for control of other STDs (Hoxworth et al. 2003), and the risk does not appear to be higher for notifying partners in regard to HIV (Kissinger et al. 2003). It is important, however, to acknowledge and minimize the possibility of harm from inadvertent disclosure when private health information is transferred from surveillance to health care providers, or when public health workers use this information during outreach efforts. Addressing the community's perception of risk is important as well (Burriss 2000).

Disclosure of private health information that is not authorized by a patient, associated with an activity that is intended to maximize health benefits, can cause a conflict between respect for persons and beneficence. Nonetheless, surveillance-based follow-up to facilitate HIV care also honors respect for HIV-diagnosed persons by helping them make informed choices about their medical care and access treatment that allows them to protect others from infection. In a recent survey, 56 percent of 136 participating HIV clinic patients expressed an interest in starting antiretroviral treatment specifically to decrease the risk of transmitting HIV to their sexual partners; the authors noted that knowledge about the effect of antiretroviral treatment on HIV transmission was not widespread in the population at the time of the survey (Dombrowski et al. 2010). By providing information that permits individuals to make choices affecting their own and their partners' health, the use of surveillance data to facilitate care expands rather than restricts autonomy (Heilig and Sweeney 2010). In addition, the use of surveillance data to improve linkage and retention in care may serve the principle of justice by helping remove impediments to fair opportunity for obtaining HIV care and treatment.

In all these examples, those features of the program that risk privacy and confidentiality are conducted without the explicit consent of the individuals exposed to the risk. King County's program is the only one

to collect additional consent: from providers on behalf of their patients. In New York City, health department staff operate as an integral part of coordinated care in major HIV care facilities. There is generally no requirement for individual consent for public health surveillance or public health practices like surveillance-based disease prevention and control activities. But the process that provides legal authorization for public health surveillance activities and disease control activities—including weighing the value of the information to the community against the risks to individuals—could be viewed as a form of public consent (Burriss et al. 2003). Nonetheless, respect for persons and an obligation to minimize risks demands a rigorous and ongoing review of procedures conducted without consent in order to decide whether ethical considerations are being appropriately balanced.

Health departments may be more successful in eliciting the cooperation of persons living with HIV to engage in lifelong continuous care if they inform them about the follow-up protocol and allow them the opportunity to opt out of contact if they wish (Chamany et al. 2009; Mairoana et al. 2012). Yet securing consent to something that entails risk is never a substitute for minimizing or eliminating that risk (Burriss 2000). The *Dictionary of Public Health* defines an acceptable risk as “a risk that has substantially smaller and/or fewer detrimental consequences than the potential hazards of alternative courses of action” (Last 2007, 4). Determining whether the risk imposed by surveillance-based direct intervention with individuals is acceptable involves considering the specific methods, such as with whom and how surveillance information is shared for the purpose of the program, as well as the measures in place to protect security and confidentiality.

The preceding examples show how the ethical burdens may vary according to how an activity is implemented. In the New York City and King County examples, health departments made the follow-up contacts, and HIV testing and care providers were engaged only in supportive roles, that is, providing additional information to help with the follow-up contacts. In the Louisiana and Washington, DC, examples, care providers made the follow-up contacts: in Louisiana, during non-HIV-related medical care visits, and in Washington, DC, through HIV medical care provider outreach. In the latter examples, follow-up contact by health care providers occurs within a context in which a patient has chosen access to health care over absolute privacy (Hodge 2006); therefore, communication initiated by the provider is expected as

a consequence of this choice. When a patient is contacted by the health department, as in the first two examples, this contact may not be, in fact or perception, a direct consequence of the patient's choice. Unless informed in advance, the patient may not associate this contact with health care and the personal benefits to be gained from optimal care. The perceived and real risk of harm also may be greater when the health department staff, rather than a patient's health care provider, makes the follow-up contact, especially if this contact is a home visit from a public health worker rather than a phone call, text message, email, or letter.

Weighing the acceptability of risk also entails weighing the risk against effectiveness. Finally, the risk may be justifiable if it is necessary, if the benefits outweigh the risk, and if the risk has been minimized to the greatest extent possible and has been explained to the public (Childress et al. 2002). Accordingly, the justification for initiating and continuing the use of surveillance data to facilitate HIV care requires the ethical considerations described next and summarized in table 2.

Evidence of Effectiveness: Does the Program Planned or in Progress Effectively Identify People Needing Care and Connect Them to Care?

The effectiveness of surveillance-based outreach to facilitate care has two dimensions: (1) whether such follow-up reaches the intended population and (2) whether the outreach actually facilitates care. The Seattle–King County example shows that the limitations of surveillance systems may limit the effectiveness of surveillance-based follow-up. In the initial years of the King County program, 77 percent of those identified as not being in care were actually misidentified because they were in care outside the jurisdiction, had died, or their CD4 and VL tests had not been reported to the surveillance system (Buskin et al. 2011). The quality of surveillance data also influenced the effectiveness of outreach in a CDC supplemental surveillance pilot project conducted from 2009 through 2010 in Indiana, New Jersey, New York City, Philadelphia, and Washington State. HIV-diagnosed people who had never received HIV care were identified through surveillance, contacted to assess barriers to care, and offered referrals to care. In the study, called the Never in Care Project, incomplete or delayed reporting of CD4 and VL tests led to the

TABLE 2

Ethical, Procedural, and Strategic Considerations for Using Surveillance and Clinical Information to Improve Linkage to and Retention in HIV Care

Ethical

- Is it necessary to use surveillance data to facilitate care?
- Are there less risky alternatives?
- Are the proposed activities effective for identifying people needing care and/or connecting them to care? Are plans in place to evaluate the program's effectiveness and possible risks?
- Are the proposed methods permitted by state law and consistent with local agreements about the conditions for using surveillance data?
- What are the known benefits and risks? Who incurs the benefits and risks?
- How can the risks be minimized?
- How will the public be engaged? How will accountability to the public be ensured?

Procedural

- What protocols should guide the collaboration of the health department's surveillance and prevention programs with HIV care providers to improve linkage to and retention in HIV care?
- What information can be shared, by whom and with whom?
- What controls are needed to protect the information and ensure its ethical use?
- What collaborations are needed inside the health department (HIV surveillance and HIV prevention programs, STD control, etc.) and with clinical and nonclinical service providers outside the health department?
- What indicators should trigger collaboration between a health department and HIV care providers, and how should the collaboration be initiated?
- How can public health programs use and share individual-level data without compromising confidentiality?
- What arrangements for ongoing evaluation are needed?
- What lessons can be learned, and what synergies can be developed by working with other local public health programs?

Strategic

- What infrastructure (technical, legal/policy, governance) and financial and human resources are needed?
 - What existing relationships, provider networks, and administrative structures support the proposed activity?
 - By what means should public health programs secure HIV care providers' commitment to collaboration?
 - How might a feedback loop be implemented to improve linkage to and retention in HIV care?
-

follow-up of a large number of persons who were already receiving HIV medical care (Bertolli et al. 2013). Furthermore, because HIV surveillance programs do not collect information on why providers are ordering CD4 and VL tests, the likelihood that a single CD4 or VL test result represents an intake visit with an HIV medical care provider is unclear (Bertolli et al. 2012). Later we explain that the alternative to using surveillance data to identify persons needing care, that is, using clinic records, also is constrained by data quality.

The reports of early work in Seattle–King County and on the Never in Care Project indicated that the quality of surveillance data improved as inconsistent and incomplete reporting issues were recognized and addressed (Bertolli et al. 2012; Buskin et al. 2011). These examples emphasize the duty to monitor the accuracy and completeness of surveillance data for identifying individuals in need of care and to weigh effectiveness against risk as part of continuing ethical scrutiny. Some programs may need to focus at first on enhancing the completeness, timeliness, and accuracy of critical data elements such as CD4, VL, and vital status before making contact with patients.

In the pilot phase of King County's expanded project, 46 percent of persons for whom providers allowed contact and 79 percent of those who were successfully contacted accepted participation in the program to promote care engagement and antiretroviral therapy (Dombrowski et al. 2013). A recently published evaluation indicates that after identification through surveillance data collected by the Louisiana Office of Public Health, patients contacted as a result of the LaPHIE Project were successfully retained in care, with the majority having at least one visit every six months and lower odds of having a VL > 10,000 copies/mL over the study period, February 2009 to July 2011 (Magnus et al. 2012). There also is evidence to suggest that several interventions involving outreach, including interventions delivered by health department disease intervention specialists, increase the likelihood of initiating or maintaining primary HIV care (Bradford 2007; Bradford, Coleman, and Cunningham 2007; Cabral et al. 2007; Naar-King et al. 2007; Rajabiun et al. 2007; Tanner et al. 2010; Zetola et al. 2009). Such evidence can justify starting surveillance-based intervention with individuals to facilitate medical care. But because the ethical burdens vary depending on the local context and the specifics of implementation and because the claim of beneficence hinges on the local availability of treatment (e.g., the ability of local clinics to accept patients, the availability of support from the

AIDS Drug Assistance Program), health departments must commit to ongoing monitoring of the effectiveness and risks of surveillance-based follow-up in their jurisdictions. This information should guide decisions about whether and how to continue the activities.

Necessity: Is It Necessary to Use Surveillance Data to Facilitate Care? Are Less Risky Alternatives Available?

If options other than using HIV surveillance data to facilitate care are equally effective and involve fewer risks to moral claims such as beneficence, autonomy, privacy, and fair opportunity, ethical obligations require choosing the less risky option (Kass 2001). HIV-infected individuals clearly need to know that they are infected and should receive regular HIV care, including antiretroviral treatment (Gardner et al. 2011). Yet individuals frequently face barriers to care as diverse as personal factors, like the fear of stigma; structural factors, like a lack of transportation; and system-level factors, like the separation of HIV testing from HIV care (Gilman et al. 2012; Mugavero, Norton, and Saag 2011; Naar-King et al. 2007; Rajabiun et al. 2007). Although health departments and health care providers do have ways of identifying HIV-infected persons needing HIV medical care and helping them connect to care that do not involve using HIV surveillance data, these generally cannot be implemented with equal coverage across a jurisdiction (Mugavero, Norton, and Saag 2011). Indeed, using population-based surveillance of CD4 and VL tests to facilitate HIV medical care may be the only option for equalizing opportunities to overcome barriers to care for all HIV-diagnosed persons in a jurisdiction.

HIV surveillance data, including HIV diagnoses and associated CD4 and VL tests, allow health departments to conduct jurisdiction-wide monitoring and coordination across the continuum of HIV care. For example, health departments might use surveillance-based outreach to mitigate barriers to care resulting from fragmentation of services, by contacting and offering assistance to persons diagnosed in care settings that do not provide ongoing HIV medical care, such as emergency departments, STD clinics, and mobile or fixed community-based testing sites. Using HIV surveillance data, health departments might identify persons who repeatedly test positive but do not begin HIV care (Hanna, Tsoi, and Begier 2009), to prioritize them for linkage

facilitation services. Health departments may be able to help providers help their patients, even in facilities offering both HIV testing and care, by distinguishing patients who have not been linked to care from those who have started care elsewhere, and those who have dropped out of care from those who have switched to another provider. In addition, through partner services, linkage facilitation, and other outreach and support programs, health departments may offer activities that complement and extend the reach of clinic-based case management and outreach staff working to engage and retain HIV-infected persons in care.

In the current environment, it is possible to make a strong argument that surveillance-based contact and intervention are necessary to meet national goals for starting and continuing HIV care. This argument may not hold up indefinitely, however, thereby necessitating the continued evaluation and justification of such follow-up activities. In the future, with the increasing adoption of electronic health records, health care providers may directly exchange data in order to identify persons needing services across a jurisdiction. Also, with the implementation of the Affordable Care Act (Patient Protection and Affordable Care Act 2010), more and more patients will be enrolled in managed care plans, be cared for by patient-centered medical homes or by Accountable Care Organizations, or be eligible for care facilitation through health homes or Ryan White Care Act–funded services. These organizations will also be charged with ensuring care and meeting care standards. Health departments' relationship to these organizations thus must be resolved.

*Proportionality (Benefits Outweigh Risks):
What Are, and Who Incurs, the Known
Benefits and Risks?*

Ultimately, arguments for surveillance-based intervention with individuals to facilitate HIV care are based on the potential benefits of that care, specifically antiretroviral treatment. Antiretroviral treatment has transformed HIV infection from a progressive, fatal disease to a chronic, manageable illness for persons who regularly access care and adhere to treatment. By suppressing viral replication, antiretroviral therapy restores and maintains HIV-infected people's good health and reduces the risk of perinatal and sexual transmission for heterosexual couples (Cohen et al. 2011; Sperling et al. 1996). The efficacy of antiretroviral treatment

for preventing HIV transmission in risk groups other than heterosexuals has not been evaluated through randomized controlled trials, nor has its effectiveness in other groups been evaluated through cohort studies. It is biologically plausible, however, that antiretroviral treatment prevents HIV infection, regardless of HIV transmission category, and population-based ecologic studies suggest that antiretroviral treatment prevents transmission among men who have sex with men (MSM) (Porco et al. 2004) and among injection drug users (Montaner et al. 2010). Results from mathematical modeling also suggest that antiretroviral treatment has a substantial potential to prevent HIV transmission in the United States, including among MSM (Blower, Gershengorn, and Grant 2000; Johnston et al. 2010; Lima et al. 2008; Sorensen et al. 2012).

People with HIV obtain maximum therapeutic benefit when they have adequate long-term adherence to antiretroviral treatment. Inadequate adherence, in contrast, may lead to subtherapeutic drug levels, partial viral suppression, transient increases in viral load, lower CD4 cell counts, treatment failure, or mortality, and it may reduce the benefits of treatment for preventing transmission (Atkinson and Petrozzino 2009; Bangsberg 2006; Bangsberg et al. 2000; Cambiano et al. 2010; Howard et al. 2002; Lima et al. 2007; Mannheimer et al. 2002; Nachega et al. 2007; Nieuwkerk and Oort 2005; Paterson et al. 2000; Simoni et al. 2006; Sullivan et al. 2007; Zaragoza-Macias et al. 2010). Suboptimal adherence may also result in antiretroviral resistance that limits options for treating the patient and his or her newly infected partners. Long-term retention in care, therefore, is needed to support high levels of adherence and maximize treatment success and prevention benefits.

Clearly, there is compelling evidence that the care and treatment of HIV-infected individuals hold substantial benefits for both them and the larger population at risk of HIV infection. Public health agencies' surveillance-based follow-up with individuals directly or through their health care providers may extend these benefits but also risks the disclosure of private information that can expose individuals to social hostility, employment discrimination, ostracism and abandonment, and domestic violence. The balance between the risks and benefits of using HIV surveillance data for intervention to facilitate care may vary across subgroups. In general, however, striking this balance may be less problematic than for some other public health interventions that limit personal autonomy—such as quarantine for untreatable infectious diseases—in which those who receive the intervention are exposed to all the risks

while others reap all the benefits. Yet the principle of beneficence demands that we consider how to minimize the risks and the principle of justice demands that we ask at the start of a surveillance-based outreach program and at periodic intervals, “Is the program being implemented fairly? How can the risks and benefits be fairly balanced?” (Kass 2001, 1780–81).

Least Infringement: How Can the Risks to Autonomy and Privacy Be Minimized?

Services to facilitate HIV medical care are intended to benefit both the individual receiving them and the public. The principle of respect for persons, however, means honoring an individual’s preference not to be contacted and/or not to receive care. When possible, such as at the time of diagnosis, HIV-infected persons should at least be informed about the follow-up protocol. And when follow-up contacts are made, the offer of assistance with obtaining care should not be coercive.

Although using HIV surveillance data to facilitate HIV care has a legitimate public health purpose, ethics demand that health departments recognize personal rights to privacy and confidentiality when they plan and implement these activities, particularly when sharing personal health information. When a provider reports a case, the health department and that provider may need to communicate about the case to complete the case report. Exchange of patients’ personal health information during such communications is justified as a routine part of surveillance. Health departments’ use of HIV surveillance data to facilitate care may expand the need for health departments and health care providers to exchange identifiable health information. For example, surveillance staff may need to communicate with health care providers to confirm that a CD4 or VL test reported to surveillance does indeed indicate that an individual attended an initial visit with an HIV care provider or that the person received these tests for referral to care. Surveillance staff may also need to check with medical care providers whether an expected CD4 or VL test missing from surveillance records was, in fact, administered. Clinic staff may need information from surveillance records to investigate whether a patient who has missed a medical appointment has missed a connection to care or had a lapse in regular care, has moved to another provider or another jurisdiction, or has died. Finally, health departments and health care providers may need to

communicate about individuals to determine who will follow up with persons identified as not receiving HIV care and how this will be done.

Sharing identifiable information collected for public health surveillance with a health care provider other than the reporting provider or sharing within the health department or with other public health agencies must be carefully considered (Fairchild et al. 2007; Heilig and Sweeney 2010). Lee and Gostin (2009) proposed ethical guidelines for collecting, storing, and using public health data that are applicable to surveillance-based linkage and retention interventions. They emphasize that policies and a governance structure should be established along with a legal infrastructure. Examples are disclosure protocols and the appointment of an oversight official to protect privacy and confidentiality and prevent “mission creep” away from legitimate public health purposes (Lee and Gostin 2009; Myers et al. 2008).

In addition, rules about how, what, and when data should be shared should be adopted as part of an ethical framework for using identifiable data for public health purposes. Fairchild and colleagues (2007) asserted that once collected, HIV surveillance data must be used, and they proposed strengthening the rules of restraint according to whether data are shared for use within or among public health agencies or with other users. The risk of sharing identifiable information from surveillance is minimized if it is being disclosed for a legitimate public health purpose and if the entity with which it is shared is governed by security protections equivalent to those used to protect the surveillance data (Heilig and Sweeney 2010).

Public Transparency: How Will the Public Be Engaged? How Will Public Accountability Be Ensured?

The uses of HIV surveillance data to facilitate linkage to and retention in HIV care should, first and foremost, conform to state and local laws. Even when the law permits this activity, health departments must first engage in discussions with providers and patients to address any concerns and establish arrangements for using surveillance data that are acceptable to stakeholders (Heilig and Sweeney 2010). From the provider’s perspective, these uses of data should strengthen patient care and support the relationship between provider and patient and should,

from the patients' perspective, help the system better meet their needs. Patients may fear that their privacy will be compromised and that they may be denied the right to refuse care, especially if the surveillance-based follow-up is not by a care provider whom they know. Both patients and providers may be concerned about interference in the provider-patient relationship. Health departments must allow these concerns to be expressed and address them in their plans for surveillance-based follow-up activities.

After a plan has been decided on and publicly vetted, the continuing engagement of stakeholders is essential to establishing the strategies, standards, and oversight of its implementation, especially with regard to communicating individual-level information. The plan for ensuring public accountability must be communicated to the public. The acceptability of using HIV surveillance data for follow-up is likely to depend on the effort (1) to clarify the scope of the information exchanged, the type of information to be exchanged, and how it will be exchanged; (2) to explain the legal foundation for exchanging information, the security measures in place to protect it, and the benefits of the exchange; (3) to understand and address any concerns about confidentiality; and (4) to build trust (Mairoana et al. 2012).

The experience in New York City, whose earlier policy of prohibiting the use of surveillance data except for epidemiologic monitoring has gradually changed after much public discussion, highlights the importance of engaging stakeholders when considering changes in the use of surveillance data and in the legal infrastructure to support the new uses (Fairchild and Alkon 2007; Myers et al. 2008). These steps are necessary when legal restrictions on the use and disclosure of surveillance information impede public health activities to address inequities in access to care and treatment, to prevent the transmission of infection, and to protect those who are exposed (Fairchild et al. 2007; Szent-Gyorgyi et al. 2012). The stakeholders' input is critical to tailoring the health department's activities to community needs. For example, Seattle–King County conducted interviews with HIV care providers and persons living with HIV. The majority of HIV-positive individuals found being contacted by the health department acceptable and said that they regarded the follow-up contact as another source of support for their care (J.C. Dombrowski, personal communication, December 21, 2012). LaPHIE, too, demonstrates the importance of formative work and a participatory approach, engaging stakeholders to build consensus and commitment and to keep

stakeholders part of a governance structure to oversee the ongoing data exchange (Herwehe et al. 2011). Finally, health departments may want to consult with an ethicist when they begin considering using surveillance data to facilitate linkage to care, as well as for ongoing ethical scrutiny.

Strategic and Procedural Considerations

Considerations for Selecting an Approach

The preceding examples show both the strengths and limitations of various approaches to balancing beneficence, autonomy, and justice. They also raise procedural and strategic considerations, which we describe next and are summarized in table 2. The early experience in Seattle–King County and the Never in Care Project illustrate that although HIV surveillance data are the best available for identifying all HIV-infected persons in a jurisdiction who are not in care, this information alone may be insufficient. Reporting delays or incomplete surveillance data may result in identifying persons already in care for follow-up contact, thereby compromising the intended balance among benefits, threats to privacy, and fair implementation, as well as reducing efficiency. Comparing surveillance and clinical records may help resolve the problems with using either surveillance or clinical records alone. An early report from Seattle–King County indicated that the health department’s efforts to find out whether the persons it sought had moved also helped improve the accuracy of surveillance data for identifying HIV-infected people not in care (Buskin et al. 2011).

In Washington, DC, providers identify those presumably needing care and, with health department staff, check this assumption against the surveillance data (West 2011). Checking is necessary because clinical data usually do not distinguish between those who have dropped out of care and those who have been lost to clinical follow-up but are receiving care elsewhere. The Washington, DC, approach conforms to more traditional “data should go in but not out” restrictions to limit access to confidential surveillance data. The real or perceived infringement on privacy by a clinic intervening with its own patients may be different from a health department intervening with those patients, even if it is on behalf of the clinic. This approach, however, may be limited to

health care facilities that share information systems or have interoperable information systems.

In the District of Columbia, the collaboration is limited to Ryan White care providers funded by the health department, a group that may be easier for a health department to engage because of their fiscal relationship and because their data systems may be similar. The Ryan White Program is the payer of last resort (Health Resources and Services Administration 2010), however, and it is the subset of persons eligible for Ryan White services who stand to benefit from this program. This clinic-initiated approach may be more challenging to implement broadly across a jurisdiction, especially by those providers that are not funded by the health department and that may use different information systems. The greater privacy of clinic-initiated follow-up must be balanced by the ability to optimize the care and outcomes for all HIV-infected persons in a jurisdiction. The benefits of a clinic-initiated approach may increase with the use of standard electronic health records and system interoperability.

The electronic data exchange central to the LaPHIE project has the advantage of being automated and being able to deliver messages in real time to quickly notify providers of those in need of treatment. In this project, as in the example from Washington, DC, intervention by a provider from whom an HIV-infected person has sought care may have fewer implications for privacy infringement than contact initiated by a public health worker. But until electronic health records are universal, interventions like LaPHIE may not provide a solution for an entire jurisdiction and may not be able to quickly link to care because they rely on patient-initiated visits. In contrast, the approaches used in New York City and Seattle–King County, in which public health workers contact those persons identified through surveillance, are more likely to pick up those not linked to care who were tested in nonclinical testing sites or in clinics that offer HIV testing but not HIV specialty care. However, mandated reporting of all CD4 and VL tests and complete and timely reporting are necessary for these approaches to be effective. Furthermore, the health departments' direct contact with these patients may be associated with a greater real or perceived infringement on privacy and autonomy. Thus the specific features of surveillance-based interventions to facilitate HIV care are important when determining whether they offer beneficence, respect for persons, and justice.

Prioritizing

Over the past decade, budget cuts have taken a toll on public health infrastructure, including reducing the workforce for outreach activities like surveillance-based follow-ups for HIV and other STDs (National Coalition of STD Directors 2011). Fewer resources make prioritizing whom to contact for follow-up an important strategic consideration. Both New York City and Seattle–King County give priority to following up with those persons with no CD4 or VL test results for a specified period or with low CD4 or elevated VL who had no medical follow-up after the CD4/VL test.

Using Follow-Up Contacts for Continuous Service Improvement

Using outreach contacts to improve services may be one way to mitigate the limitations of surveillance-based programs for promoting HIV care. Collecting consumers' experiences as part of the outreach contact, that is, what happened when they tried to obtain HIV-related services; whether they were satisfied with the services received, including public health follow-up contacts; and their suggestions for better service could help drive improvement. Using this information as part of a feedback loop of sharing information, using that information to guide changes, checking whether the changes resulted in improvements, and repeating this cycle could extend the benefits of such a program beyond the health care facilities or subgroups of HIV-infected persons contacted by the program.

Kaiser Permanente has successfully implemented feedback loops to improve linkage to and retention in HIV care, using a shared electronic health record to provide feedback on performance to regional networks and disseminating best practices across the network (Horberg et al. 2011). Applying this concept to an entire jurisdiction has been proposed as a way to resolve the missed and tenuous connections to care exacerbated by the fragmented U.S. health care system (Mugavero, Norton, and Saag 2011). We are not aware of any current efforts to systematically incorporate feedback from HIV-infected persons along with surveillance information in a jurisdiction-wide care linkage and retention improvement effort. Although all the examples described here contain some components of a feedback loop, none include all components, and none has been implemented across an entire state.

Applying lessons learned about barriers to care from ongoing follow-up contacts could be one way to make public health more effective, promote fair opportunity for HIV medical care, and balance the risks of surveillance-based outreach to facilitate HIV care.

Establishing a Legal and Policy Infrastructure and Operating Procedures

Written protocols for surveillance-based interventions to facilitate HIV care are necessary for ensuring public transparency and for implementing programs that observe ethical obligations. Policy and procedures regarding communication, follow-up, and outcomes monitoring are essential to the appropriate use of HIV surveillance data.

Communication. Policy and procedures should address communication between service providers and health department staff about HIV-infected individuals to determine whether their HIV care has been interrupted. As described, communication is needed to maximize the usefulness of information available through surveillance and clinics, because each by itself may be insufficient to document care visits (Hall et al. 2012; Jenness et al. 2012). This bidirectional communication may necessitate revising policies and standards that permit the flow of private health information from medical care providers to surveillance, with strict limitations on information flow in the opposite direction. Policies that permit data transfer both into and out of surveillance must reflect the code of restraint and ethically based principles (Fairchild et al. 2007; Lee and Gostin 2009), must include appropriate controls to protect data security, and must be publicly vetted. Input from the public is particularly important with regard to decisions about obtaining consent for follow-up. The new data confidentiality and security guidelines issued by the CDC in 2011 set standards to protect surveillance data and facilitate the sharing and uses of the data for public health action, such as the uses described in this article (CDC 2011b).

New policies must be compatible with federal and state laws. At the federal level, the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule protects most health records from disclosure but permits health care providers to disclose information to public health officials. The rule does not address the protection from disclosure of information held by public health programs, except in limited circumstances, and does not preempt state laws that may require or allow

the disclosure of data by public health authorities (U.S. Department of Health and Human Services 1996). O'Connor and Matthews found that despite some state protections, half the states have no statutes addressing the nondisclosure of personally identifiable health information held by public health agencies and, furthermore, the states' existing laws are inconsistent (O'Connor and Matthews 2011).

To support the use of surveillance data to improve linkage to and retention in care, health departments may need to examine state and local laws and regulations to identify legal or regulatory barriers to the use of public health information. Gaps in legal or regulatory infrastructure may need to be strengthened to enhance privacy protections. In addition, health departments may need to establish or strengthen operational standards and procedures to protect individual-level information exchanged with providers of medical care and of supportive services, such as linkage facilitation and case management. Federal partners such as the CDC, which is responsible for reporting progress on linkage and retention according to the National HIV/AIDS Strategy, as well as other agencies responsible for medical care and related services for persons living with HIV, such as the Health Resources and Services Administration, have a key role in encouraging these efforts.

Follow-Up. Making arrangements for follow-up is the next step after establishing an appropriate legal and policy framework and instituting procedures for identifying HIV-diagnosed persons who are not receiving or remaining in medical care. Protocols for determining who will conduct the follow-up, whether the effort will be shared, how the follow-up will be carried out, and how the risks will be minimized during follow-up contacts are necessary for coordinating activities among health departments, clinical care providers, and nonclinical service providers. When health departments are not directly involved in the follow-up to offer care facilitation services to individuals, they may still help other agencies offering these services.

Development of Best Practices

As mentioned, we have a number of tools to support the implementation of surveillance-based follow-up to facilitate HIV care, including the public health ethics frameworks, the proposed code of restraint for uses of surveillance data, and the new data confidentiality and security

guidelines issued by the CDC (CDC 2011b). The CDC recognizes the immediate need for health departments to undertake demonstration projects engaging HIV care and service providers and the community to find the best approaches for facilitating linkage and retention in HIV care for each jurisdiction. In March 2012, the CDC funded (through CDC-RFA-PS12-1201, Category C) thirty health departments to conduct demonstration projects to implement and evaluate innovative, high-impact HIV prevention interventions and strategies. This approach aims to use scalable, cost-effective interventions with a demonstrated potential to reduce new infections, in the right populations, for a major impact on the HIV epidemic (CDC 2011a). More than half these projects entail the programmatic and epidemiologic use of CD4, VL, and other surveillance data. In addition, the CDC has provided supplemental funding through HIV surveillance cooperative agreements with health departments to enhance electronic reporting and reporting of critical CD4 and VL data, to support the use of surveillance data for prevention, and to strengthen infrastructure and policies to keep data secure.

Ideally, these projects will provide more insight into effective uses of HIV surveillance and program data for engaging and retaining HIV-diagnosed persons in care, identify specific barriers to optimizing HIV prevention and treatment services, encourage communication and coordinated problem solving, disseminate innovations, and optimize the use of limited resources. These and other ongoing projects could yield best practices for implementation. Best practices should address critical ethical, procedural, and strategic considerations and should be tailored to the HIV-related public health and primary care resources, the jurisdiction's health and public health infrastructure, and relationships among local agencies.

Summary

Highly effective antiretroviral treatment is widely viewed as a powerful tool in the fight to control and prevent HIV infection. Hopes of reducing HIV incidence in the United States and improving health outcomes for people living with HIV, however, hinge on improving access to highly effective treatment and overcoming barriers to continuous treatment. Surveillance-based follow-up with individuals is an infectious disease control practice that holds promise for surmounting these problems and

represents a paradigm shift in the use of HIV surveillance data. We have highlighted the activities of several health departments that have begun to move beyond monitoring to using surveillance data for proactive linkage to HIV care and reengagement in care activities. Health departments preparing to implement such activities should review the ethical, strategic, and procedural considerations outlined here. Ongoing evaluation of activities will be necessary to ensure that they balance beneficence, respect for persons, and justice. Implementing surveillance-based approaches to facilitating HIV care more broadly will require a recommitment to cooperation, mutual respect, promotion of fair opportunity, and protection from social risk as the foundation of HIV prevention and high-quality HIV care.

References

- Arnold, M., L. Hsu, S. Pipkin, W. McFarland, and G.W. Rutherford. 2009. Race, Place and AIDS: The Role of Socioeconomic Context on Racial Disparities in Treatment and Survival in San Francisco. *Social Science & Medicine* 69(1):121–28.
- Atkinson, M.J., and J.J. Petrozzino. 2009. An Evidence-Based Review of Treatment-Related Determinants of Patients' Nonadherence to HIV Medications. *AIDS Patient Care and STDs* 23:903–14.
- Bangsberg, D.R. 2006. Less Than 95% Adherence to Nonnucleoside Reverse-Transcriptase Inhibitor Therapy Can Lead to Viral Suppression. *Clinical Infectious Diseases* 43:939–41.
- Bangsberg, D.R., F.M. Hecht, E.D. Charlebois, A.R. Zolopa, M. Holodniy, L. Sheiner, J.D. Bamberger, M.A. Chesney, and A. Moss. 2000. Adherence to Protease Inhibitors, HIV-1 Viral Load, and Development of Drug Resistance in an Indigent Population. *AIDS* 14: 357–66.
- Bayer R. 1989. *Private Acts, Social Consequences: AIDS and the Politics of Public Health*. New York: Free Press.
- Bertolli, J., P.M. Garland, E.E. Valverde, L. Beer, J.L. Fagan, and C. Hart. 2013. Missed Connections: HIV-Infected Persons Never in Care. *Public Health Reports* 128(2):117–26.
- Bertolli, J., R.L. Shouse, L. Beer, E. Valverde, J. Fagan, S.M. Jenness, A. Wogayehu, C. Johnson, A. Neaigus, D. Hillman, M. Courgen, K.A. Brady, and B. Bolden, for the Never in Care Project. 2012. Using HIV Surveillance Data to Monitor Missed Opportunities for

- Linkage and Engagement in HIV Medical Care. *Open AIDS Journal* 6(suppl. 1):M10:131–41.
- Blower, S.M., H.B. Gershengorn, and R.M. Grant. 2000. A Tale of Two Futures: HIV and Antiretroviral Therapy in San Francisco. *Science* 287(5453):650–54.
- Bradford, J.B. 2007. The Promise of Outreach for Engaging and Retaining Out-of-Care Persons in HIV Medical Care. *AIDS Patient Care and STDs* 21(suppl. 1):S85–S91.
- Bradford, J.B., S. Coleman, and W. Cunningham. 2007. HIV System Navigation: An Emerging Model to Improve HIV Care Access. *AIDS Patient Care STDs* 21(suppl. 1):S49–S58.
- Buchacz, K., R.K. Baker, F. Palella Jr., J.S. Chmiel, K.A. Lichtenstein, R.M. Novak, K.C. Wood, J.T. Brooks, and HOPS Investigators. 2010. AIDS-Defining Opportunistic Illnesses in U.S. Patients, 1994–2007: A Cohort Study. *AIDS* 24:1549–59.
- Burns, D.N., C.W. Dieffenbach, and S.H. Vermund. 2010. Rethinking Prevention of HIV Type 1 Infection. *Clinical Infectious Diseases* 51(6):725–31.
- Burris, S. 2000. Surveillance, Social Risk, and Symbolism: Framing the Analysis for Research and Policy. *Journal of Acquired Immune Deficiency Syndromes* 25:120–27.
- Burris, S., L. Gable, L. Stone, and Z. Lazzarini. 2003. The Role of State Law in Protecting Human Subjects of Public Health Research and Practice. *Journal of Law, Medicine & Ethics* 31(4):654–62.
- Buskin, S.E., E.A. Barash, A.L. Bauer, J.B. Kent, H.R. Garcia-Smith, and R.W. Wood. 2011. HIV-Infected Individuals Presumed to Not Be Receiving HIV Medical Care: A Surveillance Program Evaluation for Investigations and Referrals in Seattle, Washington State, USA. *Journal of HIV/AIDS Surveillance Epidemiology* 3(1):3.
- Cabral, H.J., C. Tobias, S. Rajabiun, N. Sohler, C. Cunningham, M. Wong, and W. Cunningham. 2007. Outreach Program Contacts: Do They Increase the Likelihood of Engagement and Retention in HIV Primary Care for Hard-to-Reach Patients? *AIDS Patient Care STDs* 21(suppl. 1):S59–S67.
- Cambiano, V., F.C. Lampe, A.J. Rodger, C.J. Smith, A.M. Geretti, R.K. Lodwick, J. Holloway, M. Johnson, and A.N. Phillips. 2010. Use of Prescription-Based Measure of Antiretroviral Therapy Adherence to Predict Viral Rebound in HIV-Infected Individuals with Viral Suppression. *HIV Medicine* 11:216–24.
- CDC (Centers for Disease Control and Prevention). 1995. Essential Components of a Tuberculosis Prevention and Control Program. *Morbidity and Mortality Recommendations and Reports* 44(RR-11):1–17.

- CDC (Centers for Disease Control and Prevention). 2008. Recommendations for Partner Services Programs for HIV Infection, Syphilis, Gonorrhea, and Chlamydial Infection. *Morbidity and Mortality Recommendations and Reports* 57(RR09):1–63.
- CDC (Centers for Disease Control and Prevention). 2010. Sexually Transmitted Diseases Treatment Guidelines. *Morbidity and Mortality Recommendations and Reports* 59(RR12):1–110.
- CDC (Centers for Disease Control and Prevention). 2011a. CDC's New High-Impact Approach to HIV Prevention Funding for Health Departments. Available at <http://www.cdc.gov/hiv/topics/funding/PS12-1201/resources/factsheet/pdf/foa-partner.pdf> (accessed June 25, 2012).
- CDC (Centers for Disease Control and Prevention). 2011b. *Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs Standards to Facilitate Sharing and Use of Surveillance Data for Public Health Action*. Atlanta: U.S. Department of Health and Human Services.
- CDC (Centers for Disease Control and Prevention). 2011c. Meeting Summary: Consultation on Monitoring and Use of Laboratory Data Reported to HIV Surveillance, March 9–10, 2011. Available at http://www.cdc.gov/hiv/topics/surveillance/pdf/Using_HIV_Laboratory_Data.pdf (accessed December 14, 2012).
- CDC (Centers for Disease Control and Prevention). 2011d. Vital Signs: HIV Prevention through Care and Treatment—United States. *Morbidity and Mortality Weekly Report* 60(47):1618–23.
- CDC (Centers for Disease Control and Prevention). 2012a. Estimated HIV Incidence in the United States, 2007–2010. *HIV Surveillance Supplemental Report* 17(4). Available at <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/#supplemental> (accessed January 24, 2013).
- CDC (Centers for Disease Control and Prevention). 2012b. Funding Opportunity Announcement: PS13-1302 National HIV Surveillance System (NHSS). Available at <http://www.cdc.gov/hiv/topics/funding/PS13-1302/index.htm> (accessed December 11, 2012).
- Chamany, S., L.D. Silver, M.T. Bassett, C.R. Driver, D.K. Berger, C.E. Neuhaus, N. Kumar, and T.R. Frieden. 2009. Tracking Diabetes: New York City's A1C Registry. *The Milbank Quarterly* 87(3): 547–70.
- Childress, J.F., R.R. Fader, R.D. Gaare, L.O. Gostin, J. Kahn, R.J. Bonnie, N.E. Kass, A.C. Mastroianni, J.D. Moreno, and P. Nieburg. 2002. Public Health Ethics: Mapping the Terrain. *Journal of Law, Medicine & Ethics* 30:170–78.

- Cohen, M.S., Y.Q. Chen, M. McCauley, T. Gamble, M.C. Hosseinipour, N. Kumarasamy, J.G. Hakim, J. Kumwenda, B. Grinsztejn, J.H. Pilotto, S.V. Godbole, S. Mehendale, S. Chariyalertsak, B.R. Santos, K.H. Mayer, I.F. Hoffman, S.H. Eshleman, E. Piwowar-Manning, L. Wang, J. Makhema, L.A. Mills, G. de Bruyn, I. Sanne, J. Eron, J. Gallant, D. Havlir, S. Swindells, H. Ribaud, V. Elharrar, D. Burns, T.E. Taha, K. Nielsen-Saines, D. Celentano, M. Essex, T.R. Fleming, and HPTN 052 Study Team. 2011. Prevention of HIV-1 Infection in Early Antiretroviral Therapy. *New England Journal of Medicine* 365(6):493–505.
- District of Columbia. 2010. Ryan White Grantees in Washington, DC: Recapture Blitz. Available at http://nationalqualitycenter.org/download_resource.cfm?fileID=36822 (accessed March 17, 2012).
- District of Columbia. 2011. Enhanced Comprehensive HIV Prevention Plan, Workbook 1. Available at http://www.cdc.gov/hiv/strategy/echpp/pdf/workbook_dc_1.pdf (accessed March 17, 2012).
- Dombrowski, J.C. 2012a. How Health Departments Promote Retention in HIV Care. *Medscape*, September 9, 2012. Available at http://www.medscape.com/viewarticle/770953_print (accessed December 21, 2012).
- Dombrowski, J.C. 2012b. Testing, Linkage and Retention in Care: Getting Control of the Cascade in Seattle. National Summit on HIV and Viral Hepatitis Diagnosis, Prevention, and Access to Care, Washington, DC, November 26–28.
- Dombrowski, J.C., M. Fleming, J. Simoni, J.P. Hughes, and M.R. Golden. 2013. Surveillance-Based Outreach to Promote HIV Care Engagement and Antiretroviral Use: Results from the Pilot Phase of a Health Department Intervention [X-244]. Conference on Retroviruses and Opportunistic Infections, Atlanta, March 3–6.
- Dombrowski, J.C., R.D. Harrington, M. Fleming, and M.R. Golden. 2010. Letter to the Editor: Treatment as Prevention: Are HIV Clinic Patients Interested in Starting Antiretroviral Therapy to Decrease HIV Transmission? *AIDS Patient Care and STDs* 24(12):747–50.
- Dombrowski, J.C., J.B. Kent, S.E. Buskin, J.D. Stekler, and M.R. Golden. 2012. Population-Based Metrics for the Timing of HIV Diagnosis, Engagement in HIV Care, and Virologic Suppression. *AIDS* 26:77–86.
- Fairchild, A.L., and A. Alkon. 2007. Back to the Future? Diabetes, HIV, and the Boundaries of Public Health. *Journal of Health Politics, Policy and Law* 32(4):561–93.
- Fairchild, A.L., and R. Bayer. 2011. HIV Surveillance, Public Health, and Clinical Medicine — Will the Walls Come Tumbling Down? *New England Journal of Medicine* 365(8):685–87.

- Fairchild, A.L., R. Bayer, and J. Colgrove. 2007. AIDS, Activism, and the Vicissitudes of Democratic Privacy. In *Searching Eyes: Privacy, the State, and Disease Surveillance in America*, chap. 7. Berkeley: University of California Press / New York: Milbank Memorial Fund.
- Fairchild, A.L., L. Gable, L.O. Gostin, R. Bayer, P. Sweeney, and R.S. Janssen. 2007. Public Goods, Private Data: HIV and the History, Ethics, and Uses of Identifiable Public Health Information. *Public Health Reports* 122(suppl. 1):7–15.
- Frieden, T.R., M. Das-Douglas, S.E. Kellerman, and K.J. Henning. 2005. Applying Public Health Principles to the HIV Epidemic. *New England Journal of Medicine* 353(22):2397–2402.
- Gardner, E.M., M.P. McLees, J.F. Steiner, C. Del Rio, and W.J. Burman. 2011. The Spectrum of Engagement in HIV Care and Its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection. *Clinical Infectious Diseases* 52(6):793–800.
- Gilman, B., J. Hidalgo, C. Thomas, M. Au, and M. Hargreaves. 2012. Linkages to Care for Newly Diagnosed Individuals Who Test HIV Positive in Nonprimary Care Settings. *AIDS Patient Care and STDs* 26(3):1–9.
- Hall, H.I., K.M. Gray, T. Tang, J. Li, L. Shouse, and J. Mermin. 2012. Retention in Care of Adults and Adolescents Living with HIV in 13 U.S. Areas. *Journal of Acquired Immune Deficiency Syndromes* 60(1):77–82.
- Hanna, D.B., R.M. Selik, T. Tang, and S.J. Gange. 2012. Disparities among US States in HIV-Related Mortality in Persons with HIV Infection, 2001–2007. *AIDS* 26(1):95–103.
- Hanna, D.B., B.W. Tsoi, and E.M. Begier. 2009. Most Positive HIV Western Blot Tests Do Not Diagnose New Cases in New York City: Implications for HIV Testing Programs. *Journal of Acquired Immune Deficiency Syndromes* 51(5):609–14.
- Harrison, K.M., R. Song, and X. Zhang. 2010. Life Expectancy after HIV Diagnosis Based on National HIV Surveillance Data from 25 States, United States. *Journal of Acquired Immune Deficiency Syndromes* 53(1):124–30.
- Health Resources and Services Administration. 2010. Eligible Individuals and Allowable Uses of Funds for Discretely Defined Categories of Services. Policy Notice 10-02. Available at <http://hab.hrsa.gov/manageyourgrant/pinspals/eligible1002.html> (accessed January 15, 2013).
- Heilig, C.M., and P. Sweeney. 2010. Ethics in Public Health Surveillance. In *Principles and Practice of Public Health Surveillance*, ed. L.M. Lee, S.M. Teutsch, S.B. Thacker, and M.E. St. Louis, 198–216. New York: Oxford University Press.

- Herwehe, J., W. Wilbright, A. Abrams, S. Bergson, J. Foxhood, M. Kaiser, L. Smith, K. Xiao, A. Zapata, and M. Magnus. 2011. Implementation of an Innovative, Integrated Electronic Medical Record (EMR) and Public Health Information Exchange for HIV/AIDS. *Journal of the American Medical Informatics Association* 19(3): 448–52.
- Hodge, J.G. 2006. The Legal and Ethical Fiction of “Pure” Confidentiality. *American Journal of Bioethics* 6:21–22.
- Horberg, M.A., L. Hurley, W. Towner, R. Gambatese, D. Klein, D. Antoniskis, W. Weinberg, P. Kadlecik, C. Remmers, R. Dobrinich, C. Quesenberry, M. Silverberg, and M. Johnson. 2011. HIV Quality Performance Measures in a Large Integrated Health Care System. *AIDS Patient Care and STDs* 25(1):21–28.
- Howard, A.A., J.H. Arnsten, Y. Lo, D. Vlahov, J.D. Rich, P. Schuman, V.E. Stone, D.K. Smith, E.E. Schoenbaum, and HER Study Group. 2002. A Prospective Study of Adherence and Viral Load in a Large Multi-Center Cohort of HIV-Infected Women. *AIDS* 16: 2175–82.
- Hoxworth, T., N.E. Spencer, T.A. Peterman, T. Craig, S. Johnson, and J.E. Maher. 2003. Changes in Partnerships and HIV Risk Behaviors after Partner Notification. *Sexually Transmitted Diseases* 30(1):83–88.
- IOM (Institute of Medicine). 2002. *The Future of the Public's Health in the 21st Century*. Washington, DC: The National Academies Press. Available at http://www.nap.edu/openbook.php?record_id=10548&page=1 (accessed March 28, 2013).
- Jenness, S.M., J.E. Myers, A. Neaigus, J. Lulek, M. Navejas, and S. Raj-Singh. 2012. Delayed Entry into HIV Medical Care after HIV Diagnosis: Risk Factors and Research Methods. *AIDS Care*, February 9 (pub ahead of print).
- Johnston, K.M., A.R. Levy, V.D. Lima, R.S. Hogg, M.W. Tyndall, P. Gustafson, A. Briggs, and J.S. Montaner. 2010. Expanding Access to HAART: A Cost-Effective Approach for Treating and Preventing HIV. *AIDS* 24(12):1929–35.
- Johnston, S.S., T. Juday, D. Seekins, T. Hebden, N. Fulcher, A.M. Farr, B.C. Chu, and C.D. Mullins. 2013. Patterns and Correlates of Linkage to Appropriate HIV Care after HIV Diagnosis in the US Medicaid Population. *Sexually Transmitted Diseases* 40(1):18–25.
- Kass, N. 2001. An Ethics Framework for Public Health. *American Journal of Public Health* 91:1776–82.
- Kissinger, P.J., L.M. Niccolai, M. Magnus, T.A. Farley, J.E. Maher, G. Richardson-Alston, D. Dorst, L. Myers, and T.A. Peterman. 2003. Partner Notification for HIV and Syphilis: Effects on Sexual Behaviors and Relationship Stability. *Sexually Transmitted Diseases* 30(1):75–82.

- Kitahata, M.M., S.J. Gange, A.G. Abraham, B. Merriman, M.S. Saag, A.C. Justice, R.S. Hogg, S.G. Deeks, J.J. Eron, J.T. Brooks, S.B. Rourke, M.J. Gill, R.J. Bosch, J.N. Martin, M.B. Klein, L.P. Jacobson, B. Rodriguez, T.R. Sterling, G.D. Kirk, S. Napravnik, A.R. Rachlis, L.M. Calzavara, M.A. Horberg, M.J. Silverberg, K.A. Gebo, J.J. Goedert, C.A. Benson, A.C. Collier, S.E. Van Rompaey, H.M. Crane, R.G. McKaig, B. Lau, A.M. Freeman, R.D. Moore, and NA-ACCORD Investigators. 2009. Effect of Early versus Deferred Antiretroviral Therapy for HIV on Survival. *New England Journal of Medicine* 360:1815–26.
- Last, J.M. 2007. *Dictionary of Public Health*. New York: Oxford University Press.
- Lee, L.M. 2012. Public Health Ethics Theory: Review and a Path to Convergence. *Journal of Law, Medicine & Ethics* 40(1): 85–98.
- Lee, L.M., and L.O. Gostin. 2009. Ethical Collection, Storage, and Use of Public Health Data: A Proposal for a National Privacy Protection. *JAMA* 302(1):82–84.
- Lima, V.D., J. Geller, D.R. Bangsberg, T.L. Patterson, M. Daniel, T. Kerr, J. Montaner, and R.S. Hogg. 2007. The Effect of Adherence on the Association between Depressive Symptoms and Mortality among HIV-Infected Individuals First Initiating HAART. *AIDS* 21:1175–83.
- Lima, V.D., K. Johnston, R.S. Hogg, A.R. Levy, P.R. Harrigan, A. Anema, and J.S. Montaner. 2008. Expanded Access to Highly Active Antiretroviral Therapy: A Potentially Powerful Strategy to Curb the Growth of the HIV Epidemic. *Journal of Infectious Diseases* 198(1):59–67.
- Losina, E., B.R. Schackman, S.N. Sadownik, K.A. Gebo, R.P. Walensky, J.J. Chiosi, M.C. Weinstein, P.L. Hicks, W.H. Aaronson, R.D. Moore, A.D. Paltiel, and K.A. Freedberg. 2009. Racial and Sex Disparities in Life Expectancy Losses among HIV-Infected Persons in the United States: Impact of Risk Behavior, Late Initiation, and Early Discontinuation of Antiretroviral Therapy. *Clinical Infectious Diseases* 49(10):1570–78.
- Louisiana Office of Public Health. 2012. Louisiana Public Health Information Exchange. Available at <http://www.lsms.org/site/images/stories/LaPhie-Non-technical%20Guide.pdf> (accessed November 4, 2011).
- Louisiana State University. 2012. LSU Health. Available at <http://www.lsuhs hospitals.org/> (accessed April 9, 2012).
- Magnus, M., J. Herwehe, D. Gruber, W. Wilbright, E. Shepard, A. Abrams, J. Foxhood, L. Smith, K. Xiao, K. DeYoung, and M. Kaiser. 2012. Improved HIV-Related Outcomes Associated with

- Implementation of a Novel Public Health Information Exchange. *International Journal of Medical Informatics* 81(10):e30–e38.
- Mairoana, A., W.T. Steward, K. Koester, C. Pearson, S.B. Shade, D. Chakravarty, and J.J. Myers. 2012. Trust, Confidentiality, and the Acceptability of Sharing HIV-Related Patient Data: Lessons Learned from a Mixed Methods Study about Health Information Exchanges. *Implementation Science* 7(1):34.
- Mannheimer, S., G. Friedland, J. Matts, C. Child, and M. Chesney. 2002. The Consistency of Adherence to Antiretroviral Therapy Predicts Biologic Outcomes for Human Immunodeficiency Virus-Infected Persons in Clinical Trials. *Clinical Infectious Diseases* 34:1115–21.
- Marks, G., L.I. Gardner, J. Craw, and N. Crepaz. 2010. Entry and Retention in Medical Care among HIV-Diagnosed Persons: A Meta-analysis. *AIDS* 24(17):2665–78.
- Millett, G.A., J.L. Peterson, S.A. Flores, T.A. Hart, W.L. Jeffries IV, P.A. Wilson, S.P. Rourke, C.M. Heilig, J. Elford, K.A. Fenton, and R.S. Remis. 2012. Comparisons of Disparities and Risks of HIV Infection in Black and Other Men Who Have Sex with Men in Canada, UK, and USA: A Meta-analysis. *The Lancet* 380:341–48.
- Montaner, J.S., V.D. Lima, R. Barrios, B. Yip, E. Wood, T. Kerr, K. Shannon, P.R. Harrigan, R.S. Hogg, P. Daly, and P. Kendall. 2010. Association of Highly Active Antiretroviral Therapy Coverage, Population Viral Load, and Yearly New HIV Diagnoses in British Columbia, Canada: A Population-Based Study. *The Lancet* 376(9740):532–39.
- Mugavero, M.J., W.E. Norton, and M.S. Saag. 2011. Health Care System and Policy Factors Influencing Engagement in HIV Medical Care: Piecing Together the Fragments of a Fractured Health Care Delivery System. *Clinical Infectious Diseases* 52(S2):S238–46.
- Myers, J., T.R. Frieden, K.M. Bherwani, and K.J. Henning. 2008. Privacy and Public Health at Risk: Public Health Confidentiality in the Digital Age. *American Journal of Public Health* 98(5):793–801.
- Naar-King, S., J. Bradford, S. Coleman, M. Green-Jones, H. Cabral, and C. Tobias. 2007. Retention in Care of Persons Newly Diagnosed with HIV: Outcomes of the Outreach Initiative. *AIDS Patient Care STDs* 21(suppl. 1):S40–S48.
- Nacheга, J.B., M. Hislop, D.W. Dowdy, R.E. Chaisson, L. Regensberg, and G. Maartens. 2007. Adherence to Nonnucleoside Reverse Transcriptase Inhibitor-Based HIV Therapy and Virologic Outcomes. *Annals of Internal Medicine* 146:564–73.
- Nakagawa, F., R.K. Lodwick, C.J. Smith, R. Smith, V. Cambiano, J.D. Lundgren, V. Delpech, and A.N. Phillips. 2012. Projected Life Expectancy of People with HIV according to Timing of Diagnosis. *AIDS* 26:335–43.

- National Coalition of STD Directors. 2011. Fact Sheet: STD Program Capacity and Preparedness in the United States: Results of a National Survey, 2009. Available at http://www.ncsddc.org/sites/default/files/fact_sheet_std_program_capacity_and_preparedness_in_the_united_states_results_of_a_national_survey_2009.pdf (accessed December 12, 2012).
- National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. 1979. *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. Washington, DC: U.S. Department of Health, Education and Welfare, April 18.
- Nieuwkerk, P.T., and F.J. Oort. 2005. Self-Reported Adherence to Antiretroviral Therapy for HIV-1 Infection and Virologic Treatment Response: A Meta-analysis. *Journal of Acquired Immune Deficiency Syndromes* 38(4):445–48.
- O'Connor, J., and G. Matthews. 2011. Informational Privacy, Public Health, and State Laws. *American Journal of Public Health* 101(10):1845–50.
- Office of National AIDS Policy. 2010. National HIV/AIDS Strategy for the United States. July. Available at <http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf> (accessed August 16, 2012).
- Palella, F.J. Jr., K.M. Delaney, A.C. Moorman, M.O. Loveless, J. Fuhrer, G.A. Satten, D.J. Aschman, and S.D. Holmberg. 1998. Declining Morbidity and Mortality among Patients with Advanced Human Immunodeficiency Virus Infection. HIV Outpatient Study Investigators. *New England Journal of Medicine* 338: 853–60.
- Panel on Antiretroviral Guidelines for Adults and Adolescents. 2012. Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents. *U.S. Department of Health and Human Services*, C4–C7. Available at <http://www.aidsinfo.nih.gov/contentfiles/lvguidelines/adultandadolescentgl.pdf> (accessed December 11, 2012).
- Paterson, D.L., S. Swindells, J. Mohr, M. Brester, E.N. Vergis, C. Squier, M.M. Wagener, and N. Singh. 2000. Adherence to Protease Inhibitor Therapy and Outcomes in Patients with HIV Infection. *Annals of Internal Medicine* 133:21–30.
- Patient Protection and Affordable Care Act. 2010. P.L. 111–148, 124 Stat. 119, March 23. Available at <http://www.gpo.gov/fdsys/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf> (accessed February 22, 2011).
- Porco, T.C., J.N. Martin, K.A. Page-Shafer, A. Cheng, E. Charlebois, R.M. Grant, and D.H. Osmond. 2004. Decline in HIV Infectivity

- Following the Introduction of Highly Active Antiretroviral Therapy. *AIDS* 18:81–88.
- Prejean, J., R. Song, A. Hernandez, R. Ziebell, T. Green, F. Walker, L.S. Lin, Q. An, J. Mermin, A. Lansky, H.I. Hall, and HIV Incidence Surveillance Group. 2011. Estimated HIV Incidence in the United States, 2006–2009. *PLoS ONE* 6:e17502.
- Rajabiun, S., R.K. Mallinson, K. McCoy, S. Coleman, M.L. Drainoni, C. Rebholz, and T. Holbert. 2007. “Getting Me Back on Track”: The Role of Outreach Interventions in Engaging and Retaining People Living with HIV/AIDS in Medical Care. *AIDS Patient Care and STDs* 21(suppl. 1):S20–S29.
- Simoni, J.M., C.R. Pearson, D.W. Pantalone, G. Marks, and N. Crepaz. 2006. Efficacy of Interventions in Improving Highly Active Antiretroviral Therapy Adherence and HIV-1 RNA Viral Load. *Journal of Acquired Immune Deficiency Syndromes* 43:S23–S35.
- Sorensen, S., S.L. Sansom, J.T. Brooks, G. Marks, E.M. Begier, K. Buchacz, E.A. DiNunno, J.H. Mermin, and P.H. Kilmarx. 2012. Mathematical Model of Comprehensive Test-and-Treat Services and HIV Incidence among Men Who Have Sex with Men in the United States. *PLoS ONE* 7(2):e29098.
- Sperling, R.S., D.E. Shapiro, R.W. Coombs, J.A. Todd, S.A. Herman, G.D. McSherry, M.J. O’Sullivan, R.B. Van Dyke, E. Jimenez, C. Rouzioux, P.M. Flynn, and J.L. Sullivan. 1996. Maternal Viral Load, Zidovudine Treatment and the Risk of Transmission of Human Immunodeficiency Virus Type 1 from Mother to Infant. Pediatric AIDS Clinical Trials Group Protocol 076 Study Group. *New England Journal of Medicine* 335:1621–29.
- Sullivan, P.S., M.L. Campsmith, G.V. Nakamura, E.B. Begley, J. Schulden, and A.K. Nakashima. 2007. Patient and Regimen Characteristics Associated with Self-Reported Nonadherence to Antiretroviral Therapy. *PLoS ONE* 2(6):e552.
- Szent-Gyorgyi, L.E., S. Desai, D. Kim, P.E. Sax, and J.O. Greenberg. 2012. Removing Legal Barriers to High-Quality Care for HIV-Infected Patients. *New England Journal of Medicine* 366:1268–70.
- Tanner, A.E., R. Muvva, R. Miazad, S. Johnson, P. Burnett, G. Olthoff, S. Jackson, D. Freeman, and J.M. Ellen. 2010. Integration of HIV Testing and Linkage to Care by the Baltimore City Health Department. *Sexually Transmitted Diseases* 37:129–30.
- Thacker, S.B. 2010. Historical Development. In *Principles and Practice of Public Health Surveillance*, ed. L.M. Lee, S.M. Teutsch, S.B. Thacker, and M.E. St. Louis, 1–17. New York: Oxford University Press.
- Thompson, M.A., M.J. Mugavero, K.R. Amico, V.A. Cargill, L.W. Chang, R. Gross, C. Orrell, F.L. Altice, D.R. Bangsberg, J.G. Bartlett, C.G. Beckwith, N. Dowshen, C.M. Gordon, T. Horn,

- P. Kumar, J.D. Scott, M.J. Stirratt, R.H. Remien, J.M. Simoni, and J.B. Nachega. 2012. Guidelines for Improving Entry into and Retention in Care and Antiretroviral Adherence for Persons with HIV: Evidence-Based Recommendations from an International Association of Physicians in AIDS Care Panel. *Annals of Internal Medicine* 156(11):817–33.
- Udeagu, C.-C., T. Webster-León, A. Bocour, P. Michel, and C. Shepard. 2012. Using Surveillance Data to Identify HIV-Positive Persons Out-of-Care (OOC) in New York City (NYC) and Offer Linkage to Care and HIV Partner Services [Abstract MOPDC0306]. XIX International AIDS Conference, Washington, DC, July 22–27. Available at <http://pag.aids2012.org/abstracts.aspx?aid=6498> (accessed January 10, 2013).
- U.S. Department of Health and Human Services. 1996. Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy and Security Rules. Available at <http://www.hhs.gov/ocr/privacy/> (accessed November 14, 2011).
- Walensky, R.P., A.D. Paltiel, E. Losina, L.M. Mercincavage, B.R. Schackman, P.E. Sax, M.C. Weinstein, and K.A. Freedberg. 2006. The Survival Benefits of AIDS Treatment in the United States. *Journal of Infectious Diseases* 194(1):11–19.
- West, T.L. 2011. Strategic Information in DC: Uses of Public Health Data for Evidence Based Programming. Available at http://www.uchaps.org/assets/DC_Strategic_Info_West.pdf (accessed March 21, 2012).
- WHO (World Health Organization). 2011. Guidelines for Intensified Tuberculosis Case-Finding and Isoniazid Preventive Therapy for People Living with HIV in Resource-Constrained Settings. Geneva. Available at <http://www.who.int/hiv/pub/tb/9789241500708/en/index.html> (accessed June 29, 2012).
- Zaragoza-Macias, E., D. Cosco, M.L. Nguyen, C. del Rio, and J. Lennox. 2010. Predictors of Success with Highly Active Antiretroviral Therapy in an Antiretroviral-Naïve Urban Population. *AIDS Research and Human Retroviruses* 26:133–38.
- Zetola, N.M., K. Bernstein, K. Ahrens, J.L. Marcus, S. Philip, G. Nieri, D. Jones, C.B. Hare, L. Hsu, S. Scheer, and J.D. Klausner. 2009. Using Surveillance Data to Monitor Entry into Care of Newly Diagnosed HIV-Infected Persons: San Francisco, 2006–2007. *BMC Public Health* 9:17.

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