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COMMENTS

A NATIONAL EPIDEMIC, A NATIONAL CONVERSATION, A NATIONAL LAW: IN SUPPORT OF UNIQUE IDENTIFIER REPORTING FOR HIV SURVEILLANCE

Kevin M. Kramer

INTRODUCTION

Acquired Immunodeficiency Syndrome (AIDS) kills. Once contracted by an individual, the disease's currently incurable state will prove fatal. Testing positive for Human Immunodeficiency Virus (HIV), the causative precursor to AIDS, may, and often does, lead to

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3. See Robert M. Wachter et al., Critical Care of Patients with AIDS, 267 JAMA 541, 541 (1992) ("AIDS is ultimately a fatal illness.").

the development of the disease. Yet today, for the first time in the near two decade-known existence of AIDS, there is considerable hope that HIV-positive individuals may never reach such a deadly denouement.

Through the combined efforts of public health initiatives and effective medical treatments, the plight of Americans with HIV is better than it has ever been. The advent of increased pharmaceutical research, heightened public awareness, combination drug therapies with protease inhibitors, and recuperative medications such as azidothymidine (AZT), all bolster the notion that the virus is treatable. Persons with HIV are living longer, more productive lives while the death rates of those whose prognosis progresses to AIDS have plummeted in the last two years.

Halting the spread of this deadly virus with all available tools is of utmost concern to public health officials. A consensus exists among

5. See Roger Doughty, The Confidentiality of HIV-Related Information: Responding to the Resurgence of Aggressive Public Health Interventions in the AIDS Epidemic, 82 CAL. L. REV. 111, 118 (1994) ("[T]he first cases of AIDS were reported in 1981.").

6. The author recognizes that HIV/AIDS is a worldwide epidemic. The disease is ravaging many parts of the world, particularly the third-world countries of Africa and Asia and nations that continually discriminate against women, homosexuals, substance abusers and the impoverished. However, for the purpose of this Comment, HIV/AIDS will be addressed solely from an American legal and epidemiological perspective.

7. See Wendy E. Parmet & Daniel J. Jackson, No Longer Disabled: The Legal Impact of the New Social Construction of HIV, 23 AM. J.L. & MED. 7, 7 (1997) (demonstrating that because of various developments in the fight against HIV and AIDS, the disease that was once considered a "plague" is now more commonly termed a "chronic disease").


9. See Burke, supra note 8, at A13. "AIDS deaths declined 23 percent, from 50,140 to 38,780." Id.

10. See id. (quoting Dr. Alonzo Plough, the director of the Seattle-King County Department of Public Health, "We need to keep our policies in line with the new scientific evidence that early notifications save lives. [Surveillance] is
public health officials and AIDS advocacy groups that the increased improvement in the lives of those with HIV is due predominantly to more effective medical treatments and not greater preventive measures. Yet, while the lives of HIV sufferers are improving, the stigmatized virus continues to spread despite greater awareness. The decrease in AIDS cases does not correspond to a proportionate decline in HIV numbers. Further, HIV is reaching epidemic proportions among minorities and women. Federal and state legislative officials are continually challenged to implement the best safety measures.

the best way for us to keep track of the epidemic and to make sure individuals and infected partners have this information.”).


12. See Baker, supra note 4, at 896. From the beginning of the epidemic, “HIV was most prevalent among male homosexuals. Thus, those who tested HIV-positive suffered a dual stigma: they were viewed as suffering from both a sexually transmissible disease and a gay disease.” Id.

13. See National Center for HIV, STD, & TB Prevention, Trends in the HIV and AIDS Epidemic, 1998 (visited Aug. 31, 1999) <http://www.cdc.gov/nchstp/od/Trends.htm#A Turning Point in the Epidemic>. In the past, CDC has primarily reported trends in the epidemic based on the estimated number of people diagnosed with AIDS each year (AIDS incidence). Until now, AIDS incidence provided a reliable picture of trends in the HIV epidemic because researchers could take into account the time between HIV infection and progression to AIDS and estimate where and how many new infections were occurring based on observed cases of disease. But with advances in treatment of HIV, AIDS incidence can no longer be used to reliably track the path of the HIV epidemic.

Id. at n.1.

14. See New HIV Data Show Impact on Women, Minorities: Numbers Take on Importance as AIDS Cases Decline, AIDS ALERT, June 1, 1998 [hereinafter New HIV Data], “When looking at new cases among people aged 13 to 24 years old, the analysis shows that 63% were African-American, [and] 44% were female.” Also, on October 28, 1998, the Department of Health and Human Services unveiled a Clinton Administration initiative “responding to HIV/AIDS in racial and ethnic minority populations.” HHS Fact Sheet, Clinton Administration Initiative to Address HIV/AIDS Among Racial and Ethnic Minority Populations, Oct. 28, 1998 (visited Nov. 1, 1998) <http://www.hhs.gov/news/press/1998pres/981028c.html>. The press release identified AIDS as the leading killer of African-American men between the ages of twenty-five and forty-four and the second leading killer amongst African-American women within the same age range. Id.
Weighing the rights of individuals against the potential safety of society continues to vex judicial officials.

Containment and combative health initiatives perpetually place the civil liberties of individuals in conflict with traditional public health measures. Discerning the relationship between the privacy and non-discrimination rights of patients and the health protections of society is the most profound issue in the history of public health. Perhaps nowhere in the arena of health law is this issue more pronounced than in the growing debate over name-based reporting of people with HIV.

In all fifty states and territories, name-based lists are maintained for people who have contracted AIDS, as well as many other sexually transmitted diseases (STDs). However, as treatments become more effective, those with HIV are living longer and the relevance of using AIDS statistics to evaluate the epidemic is drastically lower. To address this conundrum, many states are moving toward HIV reporting, either by name or a system using a numeric or alpha-numeric code called a unique identifier (UI). Though all factions of the debate—HIV/AIDS advocacy groups, gay and lesbian alliances, civil libertar-

15. See Gostin & Hodge, supra note 2, at 681.
17. See Gostin & Hodge, supra note 2, at 696-97.
18. See List of HIV Patients Raises Privacy Issues in New Jersey, THE BALTIMORE SUN, Aug. 9, 1998, at 14B [hereinafter List of HIV Patients], ("Few experts now doubt that such benefits can result from HIV reporting, much in the way that government tracking of syphilis and tuberculosis cases has gained widespread acceptance."). See also Baker, supra note 4, at 899 ("Once AIDS is acknowledged as a public health issue, then the traditional methods of disease control may be utilized. These methods include mandatory reporting. . . . The medical profession has used these methods to combat syphilis, tuberculosis, polio, and other communicable diseases.").
20. See Reporting HIV: Name-based System Is a Necessity, TELEGRAM & GAZETTE, Aug. 24, 1998, at A6 ("More than 30 states now require doctors to report to health officials the name, age, sex, race and address of any new HIV cases. A few use coding systems to preserve patient confidentiality.").
ian organizations, and public health officials—maintain that HIV surveillance is now necessary to attack the epidemic, the debate as to whether name-based or UI lists are best suited to achieve this goal is raging. While name reporting has proven to be a public health boon to states that have implemented it, there are obvious privacy and confidentiality concerns to be addressed.

This Comment argues for the reexamination and revamping of AIDS surveillance in the United States to more effectively combat the HIV/AIDS epidemic. Due to improved medical treatment, current AIDS reporting represents epidemiological information that, on average, is ten years after initial infection of HIV. This ten year lag represents a lost opportunity for states to prevent the spread of HIV. Accordingly, because HIV is demonstrably more treatable if medical care begins closer to infection HIV, surveillance provides a superior means to study the virus and improved odds for curing HIV/AIDS. Yet, proper safeguards to prevent breaches of confidentiality and adequate federal funding to finance such systems are required. To stem the spread of HIV/AIDS and protect the liberties of individuals with HIV, all states should implement a unique identifier reporting system. Considering all options available, UI reporting is the best means to combat the disease. To do otherwise will extend the life of the HIV/AIDS epidemic, unnecessarily sacrificing thousands of American lives.

Part I of this Comment examines the history of disease surveillance in the United States and explores various techniques traditionally utilized by public health officials to combat widespread epidemics. This section explains why disease surveillance is necessary and how it historically benefited the United States. It also discusses the swift implementation of national name-based reporting for people with AIDS, as well as the current shift toward HIV reporting and away from overly outdated AIDS surveillance. It chronicles the history of HIV

21. See Gostin & Hodge, supra note 2, at 688.
23. See List of HIV Patients, supra note 18, at 14B. "Public health officials say that New Jersey offers a textbook case of the value of registries of people with the AIDS virus." Id.
24. See infra notes 97-145 and accompanying text.
25. See Gostin & Hodge, supra note 2, at 686.
surveillance beginning with Colorado in 1985 to the present, in which thirty-two states maintain some form of HIV reporting.

Part II analyzes the constitutional issues pervading the name-based debate. It begins by exploring the broad discretion states possess to institute public health initiatives pursuant to the Supreme Court’s decision in *Jacobson v. Massachusetts.* In *Jacobson,* the Court “distinctly recognized the authority of a State to enact . . . ‘health laws of every description.’” Though the decision remains good law, the Court in *Griswold v. Connecticut* recognized individuals’ fundamental right to privacy in certain arenas, thus diluting the sweeping language of *Jacobson.* In addition to reconciling *Jacobson* and *Griswold,* this Part examines the possibility of equal protection and substantive due process violations through the use of name-based reporting.

Part III assesses the legal and policy considerations which ultimately deem UI reporting the most effective means to administrate HIV surveillance. Name-based lists used for AIDS reporting began almost from the disease’s inception. Modern advances in medical treatment and the widespread proliferation of personal data collection allow for the possibility of states possessing a list of HIV-infected citizens for decades. Future legislatures could enact laws which divulge this information causing *inter alia,* the potential for discrimination in employment, schools, housing, and attaining health insurance. HIV surveillance utilizing unique identifiers prevents this and negates the possibility of severe breaches of confidentiality. This Part presents a case study of UI reporting in Maryland and Texas, two states which reached different conclusions concerning the benefits of employing

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26. See id.
29. *Id.* at 25.
30. 381 U.S. 479 (1965).
unique identifiers to track HIV. The Texas and Maryland UI methodologies are presented, as are critical explanations of their systems. Part III also scrutinizes the concerns of AIDS advocacy, civil liberties, and gay/lesbian organizations regarding HIV surveillance.

Finally, Part IV recommends that the federal government should pass legislation requiring the implementation of national UI reporting. This Part proposes a reporting system that could be supported by members of the public health community, as well as HIV/AIDS advocacy and civil liberties groups. The proposal includes model guidelines from which to tailor federal legislation. Implementation of this system will arguably lead to comprehensive HIV surveillance while protecting the privacy rights of patients and the confidentiality of medical records.

I. THE HISTORICAL DEVELOPMENT OF PUBLIC HEALTH INITIATIVES IN THE UNITED STATES

A. Colonial Beginnings Through the Early 1900s

1. Early Reporting of Personal Health Information

The collection, storage, and use of information covering the health of a state or nation constitutes the core of any public health initiative. The first known example of American disease surveillance began with a 1741 Rhode Island statute requiring tavern owners to inform local health authorities about customers known to possess contagious diseases. The colony later introduced legislation mandating the reporting of such contagious diseases as cholera, yellow fever, and smallpox.

By 1850, a report on the correlation between malignancy and diseases and the living conditions of those with the diseases was submitted to the Massachusetts Sanitary Commission.

32. See id.
34. See id. at 4.
Shattuck, urged state-supported reporting of health data "by age, gender, occupation, socioeconomic level and locality." That same year, the federal government, perhaps taking a cue from England and Wales, published nationwide data on mortality. Heightened reliance on and effectiveness of mortality data led to more organized governmental health departments. Reporting began to expand from end-stage death statistics to the detection and prevention of diseases.

By the beginning of the 20th century, the federal government required all states to report on the incidence of common, deadly, contagious diseases such as small pox and tuberculosis. Over time, an arsenal of more onerous tactics was implemented across the country. These techniques ranged from the less vexatious "identifying individuals infected with an infectious agent," to the more severe "isolating and quarantining infected individuals that pose immediate hazards of contagion to others, and discovering and notifying possibly exposed persons to seek diagnosis and treatment." In 1925, mainly because differing state surveillance techniques created a hodge-podge patchwork of epidemiological data, all states submitted uniform reports on the occurrence of infectious diseases to the United States Public Health Service. The reports fueled a growing dichotomy between public health officials' duty to ensure societal safety in preventing disease and physicians' duty to honor the doctor-patient privilege of non-disclosure of sensitive, personal health information.

35. Id.
36. See Gostin & Hodge, supra note 2, at 690. William Farr, the Superintendent of the Statistical Department of the General Registrar's Office of England and Wales, reported on health data from 1839 to 1879. Id. He commented that surveillance of mortality matriculation "will be an invaluable contribution to therapeutics, as well as to hygiene, for it will enable the therapeutics to determine the duration and fatality of all forms of disease... Illusion will be dispelled, quackery... suppressed, a science of therapeutics created, suffering diminished, life shielded from many dangers." See id. (citing MILTON J. ROSENAU, Preventive Medicine and Hygiene 1002 (1917)).
37. See Gostin & Hodge, supra note 2, at 691.
38. See Gostin et al., supra note 31, at 1921.
39. Doughty, supra note 5, at 118.
40. Id.
41. See Gostin & Hodge, supra note 2, at 692.
2. Reconciling the Conflicting Interests of Individuals with Those of the Greater Population

Public health officials generally perceive their duty as one responsive to the greater good of the population.\(^\text{42}\) Physicians see their duty primarily as one maintaining the bond between themselves and their individual patients.\(^\text{43}\) Mandatory reporting requirements, therefore, while showing the appearance of talismanic preventive power,\(^\text{44}\) directly conflict with physicians' obligations under the ancient, yet still monumentally significant, Hippocratic Oath.\(^\text{45}\)

Initially, doctors adhered to the Oath, stridently opposing the disclosure of any kind of personal health information.\(^\text{46}\) Over time, this honorable intention eroded due to the public's wretched disdain for the minority of the population who contracted certain diseases.\(^\text{47}\) The crude viewpoint that "you got what was coming to you" pervaded the popular, uneducated culture.\(^\text{48}\) This common notion weighed heavily on physicians who feared the potential legal repercussions of breaching patients' confidentiality or an implied term of contract to protect medical records, or being found negligent for invasion of privacy.\(^\text{49}\) Methodically, judicial rulings\(^\text{50}\) relieved physicians of liability from

\(^\text{42}\) See id. at 693.
\(^\text{43}\) See id.
\(^\text{44}\) See Gostin et al., supra note 31, at 1921. "The eradication of smallpox, one of the 20th century's greatest public health accomplishments, was based ultimately on the prompt identification of local outbreaks and the widespread vaccination of potentially exposed persons." Id.
\(^\text{45}\) See Doughty, supra note 5, at 116, n.6. "Whatsoever I shall see or hear in the course of my profession... if it be what should not be published abroad, I will not disclose, holding such things to be holy secrets." Id.
\(^\text{46}\) See id. at 116-17.
\(^\text{47}\) See Baker, supra note 4, at 896.
\(^\text{48}\) See id. For instance, "leprosy was seen as God's punishment for venereal transgressions. Cholera was punishment for drinking and debauchery." [Citations omitted.] Id. During the onset of the AIDS epidemic, this fevered, hostile attitude reappeared as citizens exclusively associated the disease with homosexual and intravenous drug using populations. See id.
\(^\text{49}\) See Gostin & Hodge, supra note 2, at 694.
\(^\text{50}\) See generally Doe v. Marsh, 918 F. Supp. 580, 586 (N.D.N.Y. 1996). "The qualified immunity defense will protect a state actor from suit if it was objectively reasonable for that actor to believe that his actions were lawful at the time of the challenged act." Id.
such claims and medical reporting proliferated. By the 1960s, while ethical qualms still bedeviled doctors' collective conscience, halting the spread of communicable diseases appeared to outweigh individuals' interests. Today, reporting to state health officials, who in turn report to their paternal counterparts in the federal government, is commonplace.

B. Implementing Name-based AIDS Reporting

In 1981, AIDS was first diagnosed in the United States after doctors observed rare cancers and severe pneumonia among homosexual men. The Centers for Disease Control and Prevention (CDC) immediately attempted to combat the spread of the disease by instituting a nationwide tracking system. Name-based reporting, which was and is still used for a multitude of diseases, including sexually transmitted ones, was quickly adopted for tracking AIDS in all fifty states. Today, the names and other pertinent information about AIDS patients, such as age, sex, and ethnicity, are collected locally and submitted to a state’s department of health. This information (absent patient names or other individually identifying data) is then relayed to the CDC for national surveillance.

It may seem curious that gay/lesbian and civil liberties groups, the same organizations that are a driving force against name-based lists for HIV surveillance today, were virtually silent in their opposition to name reporting for AIDS during the early 1980s. However, these advocacy groups, particularly gay/lesbian associations, became more outspoken and organized only after the outbreak of HIV/AIDS. When

51. See Gostin & Hodge, supra note 2, at 695.
52. See id.
53. See id. at 696.
54. See id.
55. See Burke, supra note 8. “Names reporting has long been used to help contain and combat . . . dangerous infections. [Washington] state monitors 54 such ailments including measles, tuberculosis, whooping cough, certain types of hepatitis, and several sexually transmitted diseases.” Id.
56. See Gostin & Hodge, supra note 2, at 697.
57. See id.
58. See id.
59. See id. at 696 (“Remarkably, while advocacy groups fiercely opposed HIV reporting, they exhibited little opposition to reporting CDC-defined AIDS.”).
AIDS was first discovered, patients were primarily diagnosed in the late stages of the fatal illness when they had fleeting months to live. Consequently, when judiciaries weighed the privacy rights of individuals with a fatal disease against the interests of public health officials to halt the spread of AIDS, the public health perspective won out handily. Since it was not yet known that persons could live with HIV before progressing to AIDS (in fact, HIV was not discovered until 1983),\textsuperscript{60} citizens recognized AIDS as a disease that only afflicted homosexuals or intravenous drug users. This stigmatization resulted in AIDS sufferers' inability to find advocates to protect their right to privacy. Hence, name-based AIDS reporting soon followed in spite of individual citizens' privacy rights and confidentiality concerns.

As AIDS became a recognized disease and medical research determined persons carrying HIV could live, even asymptotically,\textsuperscript{61} for years, surveillance based solely on AIDS became less effective in tracking the HIV/AIDS epidemic. A transformation to HIV surveillance remains the next logical step. How to accomplish the task remains debatable.

\textbf{C. The Shift to HIV Surveillance}

As stated earlier, advanced medical treatments now allow HIV-positive individuals to live healthy lives indefinitely without ever contracting AIDS.\textsuperscript{62} From the point of infection, HIV actively attacks the individual's immune system, and only through rigorous therapeutic maintenance can HIV remain an inactive agent. "Early detection and treatment is critical to providing individuals infected with HIV the opportunity to live longer without visible symptoms."\textsuperscript{63} Additionally, the advances in treatment have greatly diminished the relevance of AIDS data to accurately represent the incidence of HIV.\textsuperscript{64} In 1996, national AIDS death rates fell for the first time since the known in-

\begin{itemize}
  \item \textsuperscript{60} See Gostin & Hodge, supra note 2, at 697.
  \item \textsuperscript{61} See Baker, supra note 4, at 892 ("An HIV-positive individual may remain asymptomatic for up to ten years.").
  \item \textsuperscript{62} But see Baker, supra note 4, at 891 ("[A] person infected with HIV may become sick and die before developing AIDS."); see also Edward P. Richards, Communicable Disease Control in Colorado: A Rational Approach to AIDS, 65 DENV. U. L. REV. 127, 127 n.3 (1988).
  \item \textsuperscript{63} Gostin & Hodge, supra note 2, at 699.
  \item \textsuperscript{64} See Draft Guidelines, supra note 27, at 1.
\end{itemize}
ception of the disease.\textsuperscript{65} While surely welcome news, this trend did not correlate to a decrease in HIV incidence.\textsuperscript{66} Revising surveillance to monitor the incidence of HIV among the states can provide an accurate assessment of the disease.

1. How HIV Reporting Is Conducted

Currently there are four means by which individuals may be tested for HIV. One method is through the purchase of a home test kit. While "[t]ears, saliva, blood, semen, and vaginal secretions contain the virus,"\textsuperscript{67} the most common method for home testing is by pricking the finger and placing three drops of blood on a piece of testing paper.\textsuperscript{68} The tester then mails the card to the testing site. A number is the only identifying mark accompanying the test and a person can simply call to receive his or her results via that same number.\textsuperscript{69} If the person tests negative, a recorded message provides general information.\textsuperscript{70} If the test proves positive, "a trained counselor comes on the phone and provides counseling and information concerning possible retesting, treatment, and the location of medical, legal, and counseling services."\textsuperscript{71} Under this method of testing, no data are recorded or reported to any public health entity. While this method is the most protective of privacy, it is only available to those who can afford to buy the test.\textsuperscript{72}

A second method is the use of either an anonymous test site or an anonymous physician test. At the test site, demographic information is recorded, such as race/ethnicity, sex, and age. If a person tests positive

\begin{itemize}
\item \textsuperscript{65} See id. at "History of AIDS Surveillance."
\item \textsuperscript{66} See id. at "Current Status of HIV Surveillance." See also New HIV Data, supra note 14. ("In contrast to the decline in the AIDS incidence rate, the data also show that the number of new HIV cases has remained stable.")
\item \textsuperscript{67} Baker, supra note 4, at 893.
\item \textsuperscript{68} See FDA Debates Home Test for AIDS, AIDS WEEKLY, July 4, 1994, at 6.
\item \textsuperscript{69} See id.
\item \textsuperscript{70} See id.
\item \textsuperscript{72} During the first half of 1999, home HIV tests cost approximately fifty dollars in the Washington, D.C. area. This analysis is from the author's interviews with pharmacists at ten different pharmacies in Washington, D.C. and northern Virginia.
\end{itemize}
for HIV, the aggregate information is forwarded to public health officials, absent patients' names.

Under a third method, a person goes to a confidential test site, physician's office, or hospital and identifying information is collected. In states that use name-based reporting, demographic information is recorded at the test site. If the person tests positive, the recorded data and the individual's name and address are forwarded to the state health department. The states, in turn, send this information to the CDC without names or addresses. However, in states that do not use name-based reporting, the confidential data may remain at the site, doctor's office, or hospital. This information could conceivably be forwarded to the state health department at a future date if that state later passes legislation requiring data to be recorded retroactively. Because this confidential information may remain at the physician's office or test site for an extended period of time, individuals may be driven to test anonymously or not at all.  

A fourth method is UI reporting. Under a UI reporting system, the individual visits a confidential test site, physician's office, or hospital for testing. The test site does not record the individual's name, but instead creates a UI for the patient. Elements of the numerically coded UI usually include part of a person's social security number, and codes for race/ethnicity, sex, and age. If the person tests positive, the demographic data are reported to the county or state health department by UI only. The individual's name is never reported to the health department, but rather stays at the provider level.

As of October 1, 1999, thirty-two states conducted HIV surveillance. Three states, Connecticut, Oregon, and Texas use name-based
lists for pediatric cases only. Though the number of states conducting HIV surveillance constitutes nearly two-thirds of the nation, these states collectively account for only one-third of all AIDS cases reported to the CDC through 1997. Of the ten states with the highest number of reported AIDS cases, only three, Florida, Louisiana, and New Jersey, conduct name-based HIV surveillance. The two states with the highest number of AIDS cases, California and New York, do not have any kind of HIV tracking at all. Consequently, at present, only antiquated AIDS reporting is available to study the disease and HIV infection cannot be tracked on a national scale.

2. Why HIV Reporting is Conducted

In addition to the increasingly outdated nature of AIDS reporting and its ineffectiveness to track HIV/AIDS, the shift to HIV surveillance is useful on two other fronts: studying the epidemiological and environmental factors of HIV transmission more effectively and reducing perinatal HIV transmission.

Interest groups most entangled in matters concerning the HIV/AIDS epidemic, whether they are in favor of name-based or UI reporting, agree that HIV surveillance is a needed addition to the war against HIV/AIDS. Disease surveillance "at the earliest stage of de-

76. Oregon requires reporting for HIV-positive children under the age of six years old. Connecticut and Texas report pediatric cases for children under thirteen years of age.
77. See Gostin & Hodge, supra note 2, at 710.
78. See id.
79. Although AIDS reporting, by itself, is now deemed ineffective to monitor the HIV/AIDS epidemic, it should continue to be an element in the tracking of the disease. AIDS surveillance still allows state health departments and the CDC to examine how many citizens are dying from AIDS each year and how many citizens with HIV are progressing to the terminal illness. "HIV reporting can be an important component of a comprehensive HIV/AIDS surveillance system that also includes AIDS reporting, in-depth interviews, medical record reviews, unlinked seroprevalence surveys, and sampling representative populations." Gostin & Hodge, supra note 2, at 711.
80. "Recent developments in the AIDS epidemic support the conclusion that an HIV surveillance system can now better meet the public health needs and goals than an AIDS surveillance system." Creating an Effective Public Health Response to the Changing Epidemic: Moving to HIV Surveillance by Unique Identifier and Other Non-Name Based Surveillance Systems. (A paper prepared in October 1997 in collaboration between the AIDS Action Committee of Mas-
velopment is not unusual, but is standard public health practice grounded in historical epidemiology for all other significant infectious diseases.”

a. The Benefactors of Effective HIV Surveillance

Tracking the prevalence of HIV benefits all entities involved with HIV: public health departments, health care providers, health insurance companies, and most importantly, patients and their loved ones. Through early detection, local, state, and federal health departments can study the disease by observing how an individual’s health responds over time after beginning a course of medical treatment. By reporting HIV incidence, health officials can determine which communities have a high rate of HIV and then concentrate educational seminars, free HIV screening, condom distribution, and needle sharing programs to those communities. By implementing proactive measures and providing funding with government health expenditures, better treatments and increased scientific research can move towards a cure. Purposeful testing and reporting also assist health care provid-
ers. A decreased rate of HIV means fewer people need treatment, physicians and care providers can assist other patients, and fewer hospital hours are spent with HIV sufferers.

Health insurance companies paying for expensive medications and treatments for those with HIV have a large stake in the HIV/AIDS epidemic. Increasingly competent HIV reporting systems are likewise to the companies' collective benefit. At the core of any health insurance policy existing between an individual and a plan is a binding contractual agreement. This obligation requires a person to pay periodic installments and premiums to the company in return for a promise that if certain medical circumstances occur, the insurance company will pay for the medical bills. Healthy plan holders mean fewer financial outlays for the company. Because HIV surveillance can assist in decreasing the rate of HIV, insurance companies gain monetarily when surveillance is effective.

Finally, patients and their loved ones are at the heart of early testing and confidential HIV surveillance. While HIV in the United States remains predominantly a syndrome of the gay and intravenous drug using communities, the disease can, and does, afflict people from all walks of life, regardless of sexual orientation or drug use. For this reason, periodic testing ensures that if one does contract HIV, early medical treatment can begin immediately and provide the patient the greatest chance at a healthy life. Surveillance of the epidemic allows public health agencies to identify the best treatments. This information can, in turn, be shared with physicians who can prescribe effectual medical care to those with HIV. Yet, as addressed later in this Co-

or Medicaid, government programs, and private insurance companies." Id. See also Nancy Perkins, Prohibiting the Use of the Human Immunodeficiency Virus Antibody Test by Employers and Insurers, 25 HARV. J. ON LEGIS. 275, 279-83 (1988).

84. See Blayer, supra note 8, at 1169 (maintaining that premium rates are calculated by weighing different demographic and risk factors of the individual such as age, sex, occupation, or smoking habits).

85. Insurance companies have had a intense interest in HIV testing since testing was introduced in 1985. Insurance groups certainly have a fiduciary interest, and perhaps even a duty, in charging higher rates for persons more susceptible to sickness. Most states generally allow insurers to test for HIV, but the test results are closely regulated. Among the factors considered in making regulations are: confidentiality of test results, cost of screening, and nondiscrimination in providing insurance. See id. at 1168-69.
ment, high quality surveillance and strict confidentiality of all personal HIV data must remain of the utmost importance.

b. Perinatal Transmission of HIV

Perinatal transmission of HIV is "the vertical transmission of HIV from an HIV-positive pregnant mother to her unborn fetus or infant child during birth"86 and constitutes the primary method in which pediatric cases of HIV arise.87 Screening women before they become pregnant provides the greatest incentive to shun unprotected intercourse for HIV individuals, if not for the criminal liability that may result from knowingly transmitting HIV,88 then for the risk of bearing an HIV-positive child. When HIV surveillance is used in tandem with partner notification, pregnant women possibly exposed to the virus by their partner can be tested immediately. If these women test positive, they may begin medical treatment to help prevent perinatal transmission of HIV.

Although it is unclear whether transmission takes place during pregnancy, delivery, or breastfeeding after birth,89 and which factors

86. Gostin & Hodge, supra note 2, at 701.
87. See Pamela J. Boyer et al., Factors Predictive of Maternal-Fetal Transmission of HIV-1: Preliminary Analysis of Zidovudine Given During Pregnancy and/or Delivery, 271 JAMA 1925, 1925 (1994) (positing that mother-fetus or mother-infant child transmission accounts for the most predominant means by which pediatric HIV cases occur).
88. On March 13, 1997, Rep. Tom Coburn (R-OK) sponsored a bill entitled the "HIV Prevention Act of 1997" which included a requirement of informing individuals who may have been exposed to HIV to be notified by a state public health official. See H.R. 1062, 105th Cong. (1997). Encompassed in the legislative language was a sense of the Congress that, "individuals with HIV disease have an obligation to protect others from being exposed to HIV by avoiding behaviors that place others at risk of becoming infected. The States should have in effect laws providing that intentionally infecting others with HIV is a felony." Id. at § 2(5). "[I]t is a felony for the individual to infect another with HIV if the individual engages in the behaviors involved with the intent of so infecting the other individual." Id. at § 4. This bill was designated to the House Committee on Commerce on March 13, 1997, which referred it to the Subcommittee on Health and Environment eight days later. It was never voted on before the conclusion of the 105th Congress. At the present time, similar legislation has not been introduced during the 106th Congress.
89. See Sheldon H. Landesman et al., Obstetrical Factors and the Transmission of Human Immunodeficiency Virus Type 1 from Mother to Child, 334 NEW
increase the chances of transmission, there is approximately a fifteen to thirty-five percent chance of transmission if no medical intervention takes place. However, studies of perinatal treatment show that AZT reduces the risk of perinatal transmission to roughly eight percent. Avoidance of birth by cesarean section and postnatal breastfeeding may also decrease the likelihood of transmission to the child.

II. CONSTITUTIONAL ISSUES IN THE HIV SURVEILLANCE DEBATE

The Supreme Court in Jacobson v. Massachusetts discussed the states' broad police power to protect the public from disease. In Jacobson, a Massachusetts man challenged a state statute requiring all adults to be vaccinated for smallpox after he refused to comply with the requirement. Justice Harlan wrote for the majority of the Court stating,

this court has refrained from any attempt to define the limits of [the police] power, yet it has distinctly recognized the authority of a State to enact quarantine laws and 'health laws of every description[.]' . . . According to settled principles the police power of a State must be held to embrace, at least, such reasonable regulations established directly by legislative enactment as will protect the public health and the public safety.

Under this decision, states are conceivably given free reign to establish public health programs “of every description” to combat disease provided the regulations are reasonable. More recent decisions

ENG. J. MED. 1617, 1617 (1996) (stating that most transmissions occur near delivery).

90. See Gostin & Hodge, supra note 2, at 701. “Causes of vertical transmission of HIV involve many factors, including the mother’s stage of infection and characteristics of the viral strain, incidents during delivery, and whether the mother breastfeeds.” Id.


92. See Rhonda S. Sperling et al., Maternal Viral Load, Zidovudine Treatment, and the Risk of Transmission of Human Immunodeficiency Virus Type 1 from Mother to Infant, 335 NEW ENG. J. MED. 1621, 1622-23 (1996).

93. See Gostin & Hodge, supra note 2, at 703.

94. 197 U.S. 11 (1905).

95. See id. at 14.

96. Id. at 25.
discussed infrA attempted to decipher the extent to which state regulation remained constitutional.

A. The Right to Privacy in One’s HIV Status

1. Griswold v. Connecticut

Although the United States Constitution does not explicitly establish an individual’s right to privacy, this does not mean that such a right does not exist. The Supreme Court gleaned a right to privacy vis-à-vis the penumbras of the Bill of Rights in Griswold v. Connecticut. The landmark Griswold majority interpreted the First, Third, Fourth, Fifth, and Ninth Amendments to provide a privacy right.
for citizens.

In 1965, the Griswold Court held that a Connecticut statute prohibiting married couples from using contraception violated their right to privacy. The lower courts deemed the Executive Director of the Planned Parenthood League of Connecticut to be an accessory to a married couple. The Executive Director challenged the accessory statute as a violation of the Fourteenth Amendment. The Court ruled that although it was not a "super-legislature" which delves into the reasoning behind a particular statute, it was clear that the Court shall protect certain fundamental rights, even if those rights are not explicitly stated in the Constitution. The Court cited examples such as the right of "freedom to associate and privacy in one's associations," the right to educate a child in the school of the parents' choice, and the right to study a foreign language.

people." Id.

105. See Griswold, 381 U.S. at 480, 486.

106. The section of the statutes in controversy were §§ 53-32 and 54-196 of the General Statutes of Connecticut (since repealed). Section 53-32 stated: "Any person who uses any drug, medicinal article or instrument for the purpose of preventing conception shall be fined not less than fifty dollars or imprisoned not less than sixty days nor more than one year or be both fined and imprisoned." Id. at 480. Section 54-196 provided, "Any person who assists, abets, counsels, causes, hires or commands another to commit any offense may be prosecuted and punished as if he were the principal offender." Id.


No State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any State deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.

Id.

108. Griswold, 381 U.S. at 482.

109. See id. "We do not sit as a super-legislature to determine the wisdom, need, and propriety of laws that touch economic problems, business affairs, or social conditions. This law, however, operates directly on an intimate relation of husband and wife and their physician's role in one aspect of that relation." Id.

110. Id. at 483 (citing NAACP v. State of Alabama, 357 U.S. 449, 462 (1965)).


112. See Meyer v. Nebraska, 262 U.S. 390 (1923). The Court acknowledged other fundamental rights in Aptheker v. Secretary of State, 378 U.S. 500 (1964) and Skinner v. Oklahoma, 316 U.S. 535 (1942). In Aptheker, the Court recognized the fundamental right to travel by invalidating a provision denying pass-
Balancing one’s privacy interest against the state’s police power to invade the marital bedroom, the Court held the Connecticut statute unconstitutionally violated the right of privacy.\textsuperscript{113} Pursuant to Griswold, a privacy right clearly exists within the marriage relationship.\textsuperscript{114} How far this privacy right extends remains unclear.

2. \textit{Whalen v. Roe}

\textit{Whalen v. Roe}\textsuperscript{115} addressed the issue of whether New York in an attempt to prevent an illegal drug market, could require a computerized record of the names and addresses of all persons taking certain medications.\textsuperscript{116} In \textit{Whalen}, patients and physicians brought suit to enjoin enforcement of the statute. The state countered that the statute responded to growing problems of stolen or forged prescriptions, patients attaining the same prescriptions from multiple doctors, and pharmacists negligently refilling prescriptions without checking to see how many times they were refilled.\textsuperscript{117} The district court held that the statute intruded upon “the doctor-patient relationship [which] is one of the zones of privacy accorded constitutional protection,”\textsuperscript{118} and that the law interfered with this zone with “a needlessly broad sweep.”\textsuperscript{119} The Supreme Court disagreed, holding, “the State’s vital interest in controlling the distribution of dangerous drugs would support a decision to experiment with new techniques for control. . . . It follows that

\textsuperscript{113} See Griswold, 381 U.S. at 485-86.
\textsuperscript{114} See id. at 485.
\textsuperscript{115} 429 U.S. 589 (1977).
\textsuperscript{116} See id. at 591.
\textsuperscript{117} See id. at 592.
\textsuperscript{118} Id. at 596.
\textsuperscript{119} Id.
the legislature’s enactment of the patient-identification requirement was a reasonable exercise of New York’s broad police powers.” Using the reasonable basis test, the Court declined to recognize the sacred doctor-patient relationship as a fundamental right. In balancing the privacy interests of New Yorkers taking medication against the state’s interest in quelling what it considered a widespread abuse of prescription drugs, the Court recognized two different interests. “One is the individual interest in avoiding disclosure of personal matters, and [the other] is the interest in independence in making certain kinds of important decisions.”

The Court made two points in Whalen that resonate in the HIV surveillance debate today. First, the Court concluded that the mere possibility that security breaches of medical information may occur is not, on its face, enough to find the statute unconstitutional. Second, the Court acknowledged that some New York citizens may avoid or postpone seeking medical attention due to the concerns of stigmatization and privacy. Yet, the Court stipulated that disclosure of medical information is a part of modern medicine, “even if this information could reflect poorly on the character of the patient.” Further, “[r]equiring such disclosures to representatives of the State having responsibility for the health of the community, does not automatically amount to an impermissible invasion of privacy.” Thus, future litigants arguing a name-based HIV reporting program may not rely solely on the fact that future confidentiality breaches may occur.


In United States v. Westinghouse Electric Corp., the United States Court of Appeals for the Third Circuit balanced the privacy interests of employees in their medical records against the public interest.

120. Whalen, 429 U.S. at 598.
121. Id. at 599-600.
122. See id. at 597, n.20 (citing Justice Brandeis’ opinion in New State Ice Co. v. Liebmann, 285 U.S. 262, 311 (1932) that “[T]his Court has the power to prevent an experiment. We may strike down the statute which embodies it on the ground that, in our opinion, the measure is arbitrary, capricious, or unreasonable.
123. See Whalen, 429 U.S. at 595.
124. Id. at 602.
125. Id.
126. 638 F.2d 570 (3d Cir. 1980).
est of improving occupational health and safety. After receiving a request for a health hazard evaluation from an employee of Westinghouse, the National Institute for Occupational Safety and Health (NIOSH) requested access to the company's employee medical records to determine if anyone had been exposed to dangerous chemicals at the plant. The district court held that, under Whalen, public interest granted NIOSH the authority to view medical records. The court of appeals affirmed, but provided strong language respecting the depth of the right to privacy.

Recognizing that the right to privacy is "one of the most fundamental and cherished rights of American citizenship," and that "an employee's medical records, which may contain intimate facts of a personal nature, are well within the ambit of materials entitled to privacy protection," the court held that, in this instance, the societal interest in disclosure outweighed the employee's privacy interests. To balance similar warring interests in future cases, the Westinghouse court provided seven factors to consider in deciding whether disclosure of personal information is justified: (1) the type of record requested, (2) the information it does or may contain, (3) the potential for harm by subsequent nonconsensual disclosure, (4) potential injury from disclosure to the relationship in which the record was generated, (5) the adequacy of safeguards to prevent unauthorized disclosure, (6) the degree of need for access, and (7) whether there is a statutory mandate, public policy, or other recognizable public interest militating.

127. See id. at 572.
128. See id.
129. See id. at 573. See also E. I. DuPont de Nemars & Co. v. Finkler, 442 F. Supp. 821 (S.D. W.Va. 1977) (upholding an agency's authority to view medical records needed in the public interest).
130. Westinghouse, 638 F.2d at 577.
131. Id. at 577. The court provided poignant language on the details of privacy. Two examples on the level of privacy in medical disclosures help clarify admittedly muddy waters.

We may not mind that a person knows a general fact about us, and yet feel our privacy invaded if he knows the details. For instance, a casual acquaintance may comfortably know that I am sick, but it would violate my privacy if he knew the nature of the illness. Or a good friend may know what particular illness I am suffering from, but it would violate my privacy if he were actually to witness my suffering from some symptom which he must know is associated with the disease.

Id. at n.5. (citing Fried, Privacy, 77 YALE L.J. 475, 483 (1968)).
132. See Westinghouse, 638 F.2d at 578, 580.
toward access. These seven factors may be particularly relevant if lawsuits questioning HIV surveillance, specifically name-based reporting, are initiated in the future.

4. Into the 1990s

Two recent federal cases, both out of New York, concentrated on the complex issue of whether an individual has a constitutional right to privacy in one's HIV status. In the 1994 case, *Doe v. City of New York*, the United States Court of Appeals for the Second Circuit held that persons do indeed have such a right. When the City of New York publicly revealed details of a discrimination suit settlement with Delta Airlines based on an employee's HIV-positive status, the plaintiff alleged a violation of his right to privacy. In ruling for the plaintiff, the court reasoned that because of its personal nature, the right to privacy includes an individual's right to avoid disclosure of one's health status. The ruling has special importance for those infected with HIV or AIDS because revealing one's HIV/AIDS status potentially creates great stigmatism, vigilantism, intolerance, and discrimination.

While *City of New York* held there is a constitutional right to confidentiality in one's HIV/AIDS status, *Doe v. Marsh* held it is a conditional right which may be overcome by (1) the government's interest in having or using the information or (2) a waiver of the right via an individual's prior disclosure of his or her HIV status. In 1992, the New York State Education Department published an HIV awareness document entitled, "Setting Up HIV Prevention Programs Including Persons Living With HIV/AIDS." The document contained the full names of individuals living with HIV, including those of the two plaintiffs (one male and one female). The plaintiffs argued that while both were active in the HIV/AIDS advocacy community, neither of

133. See id.
134. 15 F.3d 264 (2d Cir. 1994).
135. See id. at 267.
136. See id.
137. See id.
139. See id. at 585.
140. See id. at 586.
141. See id. at 583.
them waived their right to privacy in their HIV status.\textsuperscript{142} The defendants disputed the factual nature of this claim and argued that regardless of the plaintiffs' disclosure or nondisclosure, they were entitled to qualified immunity from suit because the right to privacy was not well-settled at the time the events took place.\textsuperscript{143} After weighing these factors, the court held that at the time of the events, it was clear the right to privacy was not absolute.\textsuperscript{144} The court stated it was unclear what exactly constitutes a waiver of a right to privacy under New York law, but found the actions of the two plaintiffs would allow a reasonable person to deem that they had waived their rights.\textsuperscript{145}

\textbf{B. Equal Protection Claims for Persons with HIV}

The Equal Protection Clause of the Fourteenth Amendment\textsuperscript{146} commands that states treat similarly situated people in a similar way.\textsuperscript{147} States are given deference when classifying citizens in drafting legislation, whether by race, sex, or sexual orientation, but may not do so arbitrarily. The Supreme Court has established three standards of review for equal protection claims: (1) strict scrutiny, where a government action must be necessarily related to a compelling interest; (2) heightened or intermediate review, when an action must be substantially related to an important government interest; and (3) a rational basis test, where an action must be rationally related to a legitimate interest.\textsuperscript{148} Laws regarding individuals with AIDS or who are

\begin{footnotesize}
\begin{itemize}
\item \textsuperscript{142} See \textit{id}. Plaintiffs argued they had never disclosed their full names and panel discussions they participated in regarding HIV/AIDS were not open to the public. \textit{id}. \\
\item \textsuperscript{143} See \textit{Doe}, 981 F. Supp. at 583. The court recalled language from \textit{Whalen} (as to the two kinds of privacy interests individuals possess), \textit{Westinghouse} (that medical records contain personal facts and are within the ambit of materials entitled to privacy protection), and \textit{Doe v. Coughlin}, 697 F. Supp. 1234 (N.D.N.Y. 1988) (which stated that “[t]here are few matters of a more personal nature, and there are few decisions over which a person could have a greater desire to exercise control, than the manner in which he reveals [his HIV status] to others.”). See \textit{id}. \\
\item \textsuperscript{144} See \textit{Doe}, 918 F. Supp. at 587. \\
\item \textsuperscript{145} See \textit{id}. \\
\item \textsuperscript{146} U.S. CONST. amend. XIV, § 1. \\
\item \textsuperscript{147} See \textit{Lindsay v. Natural Carbonic Gas Co.}, 220 U.S. 61, 83 (1911). \\
\item \textsuperscript{148} See generally, \textsc{Gerald Gunther & Kathleen M. Sullivan}, \textsc{Constitutional Law} 628-916 (13th ed. 1997). 
\end{itemize}
\end{footnotesize}
HIV-positive will most likely be evaluated using the rational basis test, that is, whether the law is rationally related to a legitimate governmental interest.

1. *A Rational Basis Test for Sexual Orientation Classification*

In 1996, the Supreme Court ruled that a Colorado constitutional amendment denying individuals who are "homosexual, lesbian, or bisexual"149 any legislative, judicial, or civil rights protections, violated the Equal Protection Clause.150 In *Romer v. Evans*,151 the Court explained that where a law neither hinders a fundamental right nor implicates a suspect class, a state statute will be upheld if it is rationally related to a legitimate state interest.152 The Colorado amendment, however, imposed serious discriminating practices upon the gay/lesbian/bisexual population, a single group of citizens, and thus did not even meet the rational basis test standard.153

In relation to how this decision could affect a suit against a state's HIV surveillance program, it would probably be of little help. The Colorado constitutional amendment explicitly named homosexuals, lesbians, and bisexuals in its language, thus separating this identifiable group from other such populations. A name-based HIV reporting system, in all likelihood, would not expressly state that HIV-positive homosexuals must have their names reported to the state health department while HIV-positive heterosexuals do not. If it did, such a statute would not surpass the rational basis test. The goal of any HIV prevention program is to stop the spread of the virus, not just stop the spread of the virus in the heterosexual community. Hence, though *Romer v. Evans* deems legislative action specifically denying gay, lesbian, or bisexual rights unconstitutional, it appears that any future action would probably have to explicitly name homosexuals or bisexuals to fail the rational basis test.

2. *A Rational Basis Test for Health Status Classification*

The Supreme Court of Alabama, in the 1998 case *Middlebrooks v.*  

150. *See id.* at 624-25.
152. *See id.* at 631. Respondents did not argue that they had a fundamental right to engage in homosexual or bisexual activity. *Id.*
153. *See id.* at 635.
State Board of Health,\textsuperscript{154} held that Alabama's statute requiring name-based reporting for individuals with HIV/AIDS did not violate afflicted persons' right to privacy or equal protection rights under the Fourteenth Amendment.\textsuperscript{155} In Middlebrooks, the Alabama health department brought suit against Dr. Mark Middlebrooks, a doctor specializing in infectious diseases, for failing to report the names and addresses of HIV-positive individuals.\textsuperscript{156} Dr. Middlebrooks countered with two arguments. First, he argued the statute mandating name-based reporting violated his patients' right to privacy in their HIV/AIDS status. Second, because manufacturers of confidential HIV-testing kits are similarly situated to him, but do not have to report names or addresses, the statute violated the Equal Protection Clause.\textsuperscript{157}

Citing Whalen and the Westinghouse factors, the court ruled "the prevention of the spread of HIV and AIDS is a legitimate governmental interest, and . . . the State can require disclosure to representatives of the State having responsibility for the health of the community, and that the disclosure required . . . does not amount to an impermissible invasion of privacy."\textsuperscript{158} Regarding the Equal Protection challenge, the court held that out-of-state testing laboratories are not similarly situated to in-state physicians who test for HIV/AIDS. The court emphasized that out-of-state testing labs do not know the identity of the persons being tested and the kit manufacturers do not know the identity of those purchasing the kits. Hence, the Supreme Court of Alabama held that the state's name-based reporting statute violated neither HIV-positive persons' right to privacy nor physicians' rights under the Equal Protection Clause.

This ruling clearly strikes against future litigants who may challenge name-based reporting statutes. As long as the state and/or federal legislation provides adequate confidentiality provisions, a court applying the Westinghouse factors in a right to privacy claim will probably rule in favor of sustaining the statute. Further, the final factor, "[w]hether there is an express statutory mandate, articulated public policy, or other recognizable public interest militating toward ac-

\textsuperscript{154} 710 So. 2d 891 (Ala. 1998).
\textsuperscript{155} See id. at 891-92.
\textsuperscript{156} See id. at 891.
\textsuperscript{157} See id.
\textsuperscript{158} Id. at 892.
cess,” appears broad enough to allow a name-based reporting system.

The Equal Protection Clause may provide a stronger argument. In Middlebrooks, the court only analyzed the different treatment of an in-state physician against an out-of-state laboratory to determine if the entities were “similarly situated.” The court stated that the Equal Protection Clause does not necessarily require that a statute apply equally to all persons. The court left for another day the determination of whether an in-state doctor and an in-state lab or vendor are “similarly situated.”

C. A Substantive Due Process Claim on the Basis of HIV Status

Another possible claim in a suit against an invasive HIV surveillance system arises from the Due Process Clause of the Fourteenth Amendment. This type of argument, however, will probably prove fruitless. The Due Process Clause is cited when the Court addresses fundamental rights of individuals. As previously discussed, the Court recognizes the right to privacy, to marry, to procreate, to learn a foreign language, and for parents to send their children to private school as fundamental rights. Presumably the right to contract HIV could be argued as a fundamental right, though it would most certainly be a tough argument to make and probably be an unpersuasive one. To find a fundamental liberty, the Court has set as a standard those rights which are “implicit in the concept of ordered liberty,” such that “neither liberty nor justice would exist if [they] were sacrificed,” or those typified as “deeply rooted in this Nation’s history and tradition.” Clearly, having a disease does not go to the core of ordered liberty and such liberty would still exist if citizens did not have the disease. Further, assuming arguendo that it did, since AIDS was first discovered

159. Westinghouse, 638 F.2d at 578.
160. Middlebrooks, 710 So. 2d at 892.
161. See id. at 893 (citing McClendon v. Shelby County, 484 So. 2d 459, 464 (Ala. Civ. App. 1985)).
162. U.S. CONST. amend. XIV, § 1. The author recognizes that future litigants may argue other constitutional claims not raised in this Comment. This Comment does not mean to present an exhaustive list of arguments, but only those arguments individuals challenging an HIV surveillance program might bring forward.
163. See supra, notes 97-145 and accompanying text.
in 1981 and HIV in 1983, HIV/AIDS status is certainly not rooted in
the United States' history and tradition. Arguing a fundamental right
to privacy of medical records will also prove unhelpful when consid-
ering the Westinghouse factors. Given these past cases, the Supreme
Court is very reluctant to recognize new fundamental rights. 165

III. NAME-BASED VERSUS UI-BASED HIV REPORTING
SYSTEMS

HIV reporting, to be successful, must respect individuals' privacy
without significantly limiting the utility of surveillance. Public health
authorities must follow the least intrusive disclosure principle. Under
this principle, the information disclosed must be the narrowest in
content, least identifiable, and presented to the fewest number of per-
sons as reasonably necessary to achieve the stated purpose. Most
public health authorities, gay/lesbian and HIV/AIDS advocacy organi-
zations, and civil liberties groups agree that HIV reporting is an im-
portant public health objective. 166 Under debate is the means by which
HIV reporting should be accomplished: by name or unique identifier.
Name-based reporting relies on the disclosure of an individual's name,
address, and other identifying characteristics. Reporting by unique
identifier strips identifying information from a reporting record, rely-
ing instead on a numeric or alpha-numeric code to report cases of HIV
infection. Considering constitutional and public policy arguments in
their totality, UI reporting provides the best means to implement HIV
surveillance.

165. See id. at 194. Justice White, writing for the Court in Bowers, indicated
that the Court is not
inclined to take a more expansive view of our authority to discover
new fundamental rights imbedded in the Due Process Clause. The
Court is most vulnerable and comes nearest to illegitimacy when it
deals with judge-made constitutional law having little or no cogni-
zable roots in the language or design of the Constitution. ... There
should be, therefore, great resistance to expand the substantive reach
of those Clauses.

Id. at 194-95.

166. See Lynda Richardson, AIDS Group Urges New York To Start Reporting
of H.I.V., N.Y. TIMES, Jan. 13, 1998, at A1 (announcing the new position of the
nation's leading AIDS service agency, which now supports confidential report-
ing of HIV-positive individuals to the state health department).
A. Lessons From Texas and Maryland

I. A Texas-sized Debate

In January 1998, the Bureau of HIV and STD Prevention (Bureau) of the Texas Department of Health (TDH) recommended a change in the reporting of HIV infection in Texas from a UI system to a name-based system.167 More than 4,000 letters were mailed out by the TDH inviting citizens to participate in five public meetings in February 1998.168 In response to this invitation, the Bureau received letters, e-mail messages and telephone calls with comments from advocacy groups, providers of HIV services, legislators, members of the afflicted communities, and public health workers.169 Though no consensus arose as to which type of HIV surveillance system should be used in Texas,170 the TDH decided to propose a name-based reporting system for HIV infection.171

Citizens and advocacy groups within the state expressed several concerns during TDH's notice and comment period. One concern was that implementation of name-based HIV reporting would cause a decrease in testing.172 Several groups worried that name-based reporting would deter groups such as immigrants, the disfranchised, women, gays, lesbians, bisexuals, substance abusers, and persons from rural areas from testing. Responding to this concern, the TDH recommended that anonymous testing remain available to Texas citizens.173 Current law in Texas now mandates that all publicly-funded HIV centers provide both confidential and anonymous testing options.174 The TDH stated that this policy would not change in the future. Based on the public outcry in Texas, it is evident that any state choosing to im-

168. The meetings were held in Austin (2), Arlington, Houston, and Lubbock.
169. See Texas Department of Health, supra note 167.
170. See id.
171. See id.
172. See id.
173. See id.
174. See Texas Department of Health at 2-3.
plement HIV surveillance must make anonymous testing for HIV/AIDS a component in the system.

The availability of anonymous testing is a necessary element for any state choosing to track the HIV/AIDS epidemic. While it behooves states to count as many HIV-infected citizens as possible in its registry, a far greater concern is ensuring that individuals are not discouraged from being tested. The purpose of HIV reporting is not to count every last infected person, but rather to compute reliable prevalence and incidence rates in communities. If a state employs a combination of name-based reporting and anonymous testing, it will provide reliable HIV data and promote testing among all of its citizens.

2. *A Fair Assessment*

Those participating during the comment period raised concerns that neither the length of time nor the government funds allocated to build Texas’ UI-based reporting system were adequate to provide the state with a fair assessment of its utility.\(^{175}\) The TDH responded that the UI system lasted for four years, a period long enough to adequately review how well or poorly the system worked.\(^ {176}\) Furthermore, TDH considered the level of funding from state and federal programs sufficient to manage UI surveillance.\(^ {177}\) Based on these factors, TDH concluded the UI-based reporting system would not have been more successful had there been more funding.\(^ {178}\)

Four years and four million dollars, on the surface, may appear to be an adequate amount of time and investment to allow for an honest review of the UI-based system. Yet, a larger issue to address is that time is of the essence in combating the HIV/AIDS epidemic. Texas state health officials argued that it would not serve the needs of the HIV-afflicted community to discover in four years time that yet another experimental system did not work, thereby leaving Texas with outdated, incomplete data. A UI system, even if begun from scratch, seemingly would not take four additional years to implement and adequately assess. Texas health officials believed that a new UI-based strategy would take this long to appraise, yet shockingly did not raise the same concerns about waiting this long to evaluate a new name-

\(^{175}\) See id. at 9.
\(^{176}\) See id.
\(^{177}\) See id. at 10.
\(^{178}\) See id.
based system. Because Texas already experimented with UI-based surveillance, the Bureau and TDH should build upon its experiences instead of scrapping the program entirely. An adequately funded UI-based system using state and federal dollars would not take four additional years to review. An effective HIV UI-based reporting system could, and should, result.

3. Security and Confidentiality of HIV Data

The biggest concern addressed during TDH’s comment period was the lack of a guarantee that data collected would be secure. Understandable arguments were put forward stating that discrimination would be rampant in Texas. For example, health insurance companies could choose not to insure HIV-positive individuals. Apartment buildings and real estate brokers could shun potential renters or buyers of residences if an individual’s HIV status was known. Employers could deny offers. Immigration officials could work to deport legal immigrants. Further, family and friends who may not be privy to a relative’s condition could gain access to this information and ostracize him or her.

The TDH conceded it is impossible to guarantee that unauthorized releases of HIV information will never happen. Prior handling of sensitive medical information in Texas supports the notion that breaches of confidentiality are extremely unlikely. Yet, this does not mean breaches may never occur. The TDH maintained name-based public health reporting systems for AIDS since 1983 without a single breach attributable to the AIDS surveillance system in Texas. However, with HIV-positive individuals’ ability to live with the virus for decades, the possibility that breaches could occur would also exist for decades. Additionally, there is no guarantee future lawmakers would not pass legislation to reveal the identities of HIV-positive citizens.

179. See Texas Department of Health at 5.
180. See id.
181. See id.
182. See id.
183. See id. at 5-6.
B. The Maryland Experiences

1. Maryland’s Methodology

Since June 1, 1994, Maryland has utilized a UI system to conduct HIV surveillance that continually undergoes evaluation and refinement. Maryland reporting encompasses a six-part system: (1) the health care provider, be it a private physician, test site, or hospital, sends a blood sample to a laboratory test after creating a UI; (2) the lab sends the UI report form to the State AIDS Administration if the result indicates an HIV-positive outcome; (3) the Maryland AIDS Administration looks to see if the twelve-digit UI matches any other UI in the State AIDS Registry; (4) the Administration maintains the Registry and determines new HIV cases; (5) if necessary, Administration staff members call physicians to obtain additional information, such as clinical status and risk category, but names and addresses are not divulged; and (6) the Registry is periodically forwarded to the CDC for national surveillance without names or addresses.

2. Completeness of Records

A common criticism of UI-based surveillance is that the numbers that make up the UI are not easily attained, specifically the social security number of the person being tested. Many patients may be apprehensive to divulge these private numbers, thus creating an incomplete UI number. During the first six months of Maryland’s experience with the UI system, UI forms were sixty-one percent complete, but improved to seventy-seven percent during the last six months of 1996. The Maryland AIDS Administration believes that it will im-

185. See id.
186. See Gostin & Hodge, supra note 2, at 739-40 (noting that Texas and Maryland did not provide the four-digit social security component of the UI in approximately twenty-two percent of the cases reported). But see id. at 712. ("[W]e continue to have reservations about named-based HIV reporting. The benefits of HIV reporting are not always clear, and the potential for violation of individual rights remain[s].").
187. See The Maryland Lesson, supra note 184, at 3. From the first six
prove further upon the seventy-seven percent completion rate. In a pilot program, staff members at all confidential testing sites were trained to improve the state's completion data. After completion of the training sessions, UI completeness statistics improved to a 96.6 percent. These statistics demonstrate UI systems can work effectively when proper education is provided. Such training could be implemented in all states that choose to use UI-based reporting, rendering UI surveillance the superlative means by which to track HIV incidence.

IV. A COMPROMISE STATUTE

This Comment supports UI-based HIV reporting, but whether states should implement a UI-based or name-based system does not have to be a polarizing issue. Middle ground exists that could bring about an appropriate medium agreeable to public health officials, HIV/AIDS and gay/lesbian advocacy groups, and civil liberties organizations. This section attempts to bridge the current chasm between the two factions by suggesting model federal statutory guidelines which support UI-based reporting and provide the necessary precautions to make these guidelines effective.

A. Provide for Anonymous Testing

HIV/AIDS is a nationwide concern. This medical condition affects all persons, regardless of their sexual orientation, gender, or use of narcotics. Although advances in medical treatment have reduced new AIDS cases and AIDS death rates, this improvement on the AIDS front has not been seen on the HIV front. Proper safeguards to protect confidentiality of persons' HIV/AIDS status must be included to ensure that a proper federal UI-based surveillance bill is passed into law.

Any Congressional bill should encourage states to create or main-

months in 1994 to the last six months in 1996, all components of the UI improved as to completeness: social security reporting from 69.6% to 84.5%, date of birth from 95.2% to 98.8%, sex from 96.8% to 99.4% and race/ethnicity from 61.3% to 76.5%. See id.

188. See New HIV Data, supra note 14 ("When looking at new cases among people aged 13 to 24 years old ... [m]ore than one-quarter (26%) of the cases were from heterosexual transmission, 31% from men having sex with men, and 6% from injection drug use.")
tain sites where individuals can receive anonymous HIV tests. Offering such testing opportunities will "provide another route of access to the health system and encourage a slice of the population that has steered away from the system to enter it." This opportunity meets the public health imperative that people potentially exposed to HIV will have ready access to testing, and if necessary, treatment.

It would be best if every person who tested for HIV did so at a confidential test site. This would allow for the best tracking of the virus and allow states to implement education seminars, condom distributions, needle exchange programs, and other public initiatives best tailored to combat the epidemic. Although privacy and confidentiality breaches by states with UI-based lists are rare, keeping anonymous testing sites open would alleviate this anxiety of those being tested.

B. Partner Notification Qualifications

When a person tests positive for HIV, health workers should encourage him or her to divulge the names of any individuals that person may have infected. The health worker can then contact those people and urge them to be tested. Yet, mandating that a person divulge these names could clearly drive HIV underground and completely undermine the goal of the legislation: to have as many citizens as possible be tested for HIV. Guidelines reconciling privacy fears with public health concerns can be crafted.

189. See Doughty, supra note 5, at 179.
190. Id.
191. See AIDS: The Need To Know, CHICAGO SUN-TIMES, Sept. 16, 1997, at 21 ("[T]he prestigious New England Journal of Medicine is urging mandatory reporting. Such a policy, it says, will increase the chances that those infected with HIV will get early treatment. Like syphilis and gonorrhea, HIV is a communicable, sexually transmitted disease and should be reported to state health officials, just as those diseases are.").
192. See Privacy in H.I.V. Reporting, N.Y. TIMES, Oct. 24, 1997, at A30 ("A national reporting requirement would allow authorities to track the disease better, target prevention services to vulnerable populations and allocate medical resources more effectively.").
193. See Stay Focused on Names to Help Track HIV Cases, SEATTLE TIMES, Oct. 20, 1998, at B4 ("That sort of grotesque tampering with confidential information would not be tolerated.").
194. See Privacy in H.I.V. Reporting, supra note 192 ("Unless confidentiality can be guaranteed, a reporting requirement will very likely deter people from being tested and seeking medical care.").
Federal partner notification guidelines should be established with state adherence to these guidelines required to receive federal funding for HIV surveillance programs.\textsuperscript{195} Such specifications should mandate the anonymity of HIV-positive individuals when other persons are contacted.\textsuperscript{196} Partner notification programs could ensure this by guaranteeing that those charged with notifying others do not have access to the name of the patient who identified the possibly infected person.\textsuperscript{197}

Many reasons exist for taking this precaution. There is the obvious rationalization that HIV-positive persons would not want their names divulged to the public, even if the public in this instance is one partner. Two examples include the threat of violent retaliation against the person who infected someone or a jilted individual possibly sending an anonymous letter to an HIV-positive individual's neighbors, family, co-workers, landlord, or health insurance plan. Discrimination and stigmatization could easily follow causing the irreparable harm to the person who initially disclosed the name.

Lastly, of course, HIV/AIDS can be contracted from heterosexual sex or a tainted blood transfusion, but unprotected homosexual intercourse, particularly between gay men, and the sharing of needles during intravenous drug use present more common threats of contracting the virus. If partner notification is part of any UI-based HIV reporting bill, a caveat must be included granting immunity to any person contacted by a health care worker from any drug possession or archaic state sodomy law. Again, this provision would help to ensure the greatest number of individuals come forward voluntarily for HIV testing.

V. CONCLUSION

Better medical treatments are causing the number of AIDS deaths to rapidly decrease and those infected with HIV are living longer lives. Attention must now turn, along with heightened medical research to produce a cure, to greater preventive measures to halt the continued spread of the AIDS virus. A chief objective in the United States must be to institute the most efficient and effective means to combat the HIV/AIDS epidemic, while remaining conscious of the privacy and confidentiality rights of individuals. Doing so works to prevent the

\textsuperscript{195} See Doughty, supra note 5, at 180.
\textsuperscript{196} See id.
\textsuperscript{197} See id.
spread of HIV, while protecting HIV-positive persons from vigilan-
tism as well as from the potential of discrimination in the workplace,
in attaining housing, or while acquiring health insurance. When pri-
vacy guarantees are implemented and state systems are adequately
funded, UI-based HIV reporting surveillance currently provides the
best means to stem the tide of HIV transmission. Collaboration be-
tween HIV/AIDS advocacy groups, public health officials, and Con-
gressional leaders is necessary. Through the combined efforts of these
entities, UI-based reporting provides the best chance that HIV/AIDS
can be eradicated.