COMMENT

Public Health Versus Civil Liberties: Washington State Imposes HIV Surveillance and Strikes the Proper Balance

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In Washington State, there are approximately 8,500 recorded cases of AIDS1 or asymptomatic HIV.2 It is estimated that there are an additional 6,000 to 8,000 HIV infected individuals residing in the state.3 In 1996, HIV was responsible for the deaths of 15% of men ages 35-44, 13% of deaths among men ages 25-34, and 4% of deaths of women ages 25-34.4 According to the Center for Disease Control (CDC), efforts to stop the spread of the disease are inhibited by individuals who remain unaware of their HIV status.5

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1. AIDS is a syndrome of the immune system characterized by opportunistic diseases. The syndrome is caused by the human immunodeficiency virus (HIV), which is transmitted by exchange of body fluids (notably blood and semen) through sexual contact, sharing of contaminated needles, accidental needle sticks, contact with contaminated blood or transfusion of contaminated blood/blood products. STEDMANS'S MEDICAL DICTIONARY 39 (25th ed. 1995).


3. Id.


On July 14, 1999, after extensive deliberations, the Washington State Board of Health unanimously voted to implement a system of HIV case reporting in the state. The objectives of this plan include monitoring the spread of the disease and connecting HIV positive individuals with medical care and counseling. On September 1, 1999, the new regulations in the Washington State Administrative Code went into effect. The regulations mandate that health officials report all cases of certain specified infectious diseases, including asymptomatic HIV infection, to local health departments. Upon the adoption of the HIV surveillance program, Washington became the thirty-fourth state to mandate some form of HIV case reporting.

Although Washington is not alone in its regulatory effort to stop the spread of AIDS, the recently adopted regulations stand apart from those imposed in other states. Among the states that have HIV surveillance programs, the majority mandate HIV case reporting by patient name. By contrast, Washington's HIV surveillance system achieves the proper balance between public health and civil liberties: by using a hybrid system of both unique identifiers and patient names in HIV tracking, Washington's health regulations protect the privacy interests of HIV infected individuals in a manner that encourages testing while still promoting AIDS awareness and maintaining accurate data to aid in controlling the epidemic.

Under Washington's model, the reporting of HIV-infected individuals' names is limited to the local level. Names are provided to county health officials who are responsible for encrypting patient medical data into codes. Once codified, the data is released to state health departments for surveillance.

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8. WASH. ADMIN. CODE §§ 246-100-016, 246-100-036, 246-100-041, 446-100-072, 246-100-076, 246-100-206, 246-100-207, 246-100-208, 246-100-209, 246-100-236 (1999). Throughout this Comment, these provisions will be referred to collectively as "the regulations."
9. Under the regulations, other reportable conditions include: tuberculosis, whooping cough, measles, rabies, plague, cholera, hepatitis, and syphilis. Currently, over fifty infectious diseases are reportable in Washington state.
10. Reportable Diseases and Conditions, WASH. ADMIN. CODE § 246-100-076(5) (1999) ("Effective September 1, 1999, health care providers are required to report to the local health department all cases of HIV infection consistent with the provisions of WAC 246-100, provided the HIV-infected person receives health care or treatment services on or after September 1, 1999, regardless of the date of initial diagnosis. Local health officials will report asymptomatic HIV infection cases to the state health department according to a standard code developed by the state health department.").
12. See generally WASHINGTON STATE BD. OF HEALTH, supra note 4.
14. Id.
officials who are responsible for reporting to the CDC. 15 This procedure, which is new among states that employ methods of encryption, eliminates the possibility that sensitive medical data will be released to state government officials. 16

This Comment examines the controversy surrounding the Washington HIV surveillance system in light of a long-standing conflict between public health concerns and civil liberties. 17 Part I of this Comment briefly describes the inception of the AIDS epidemic. Part II focuses on AIDS legislation and the justifications for surveillance. Part III discusses the tension between public health and civil liberties. Part IV describes AIDS' social stigmatization and deterrence. Part V addresses the nature of medical information and the potential for government misuse. Part VI describes the types of HIV surveillance available and the benefits and burdens which accompany both tracking systems. Part VII addresses the Washington State approach to HIV surveillance and the process by which the Washington legislature drafted the regulations.

I. AIDS: THE INCEPTION OF A WORLDWIDE CRISIS

In June of 1981, the first AIDS cases were reported. 18 "From 1981 on, the number of AIDS cases doubled every six months, concentrated largely but not exclusively in the urban centers of New York, Miami, Los Angeles, and San Francisco." 19 After receiving an increasing number of reports of pneumonia and rare forms of cancer, the CDC 20 reported the cause to be a transmissible agent spread in a manner similar to hepatitis B. 21 The CDC recognized this group of diseases as what is currently known as AIDS. 22

15. Id.
16. Id.
19. June E. Osborn, The AIDS Epidemic: Discovery of a New Disease, in AIDS AND THE LAW 17, 19 (Harlon L. Dalton et al. eds., 1987) ("[I]n 1987 more new cases of AIDS were diagnosed than in the prior six years. By December 1986, nearly 50,000 people with AIDS had been reported to the Centers for Disease Control (CDC). More than half of them (27,909) had died, and indeed the mortality rate is almost 80 percent for people in whom AIDS was diagnosed more than two years ago.").
AIDS typically appears in the young adult population. The average age at the time of diagnosis is thirty-six. The majority of HIV infections result from unprotected sexual intercourse with an HIV infected partner or from sharing needles with HIV infected persons. However, the face of AIDS is changing. AIDS is not, as previously thought, a syndrome isolated within the homosexual community. Rather, AIDS has infiltrated ethnic minority populations and increased rapidly among heterosexuals. Although incidences of infection are more prevalent in men than women, cases among women are rising steadily. As HIV infection spreads among the female population, the virus finds its way into another generation as women transmit the virus to their infants prior to birth.

Diseases that have virtually no effect on healthy individuals prove deadly to infected individuals. HIV results in progressive damage to a person's immune system. The virus leaves the body susceptible to numerous opportunistic infections that result in immunosuppression. The culmination of this damage results in a manifestation of AIDS and, ultimately, death.

In addition to a grueling process of psychical deterioration, victims of AIDS often suffer from social and emotional torment. Infected persons may fear social stigmatization and various forms of implemented surveillance program for the disease, now referred to as AIDS. The CDC created a case definition for the syndrome and cases were directly reportable to the center. However, as AIDS spread, surveillance became a task for the states. State health departments forward surveillance results to the CDC, which produces a national date service.) Lawrence O. Gostin et al., National HIV Case Reporting in the United States—A Defining Moment in the History of the Epidemic, 337 NEW ENG. J. MED. 1162 (October 16, 1997) (emphasizing that the United States is at a critical point in the AIDS epidemic where it is necessary to install a national HIV surveillance system).

22. Center for Disease Control, supra note 20, at 507.
23. King County Pub. Health, supra note 2.
24. Id.
25. See Howe & Jensen, supra note 18, at 10 (emphasizing that the death rates among African American men and women are significantly higher than those among whites in the same age group).
27. Id. at 24.
29. Richard Green, The Transmission of AIDS, in AIDS AND THE LAW 28, 29 (Harlon L. Dalton et al. eds., 1987) ("HIV invades and kills the white blood cells, known as T-helper cells, that are primarily responsible for preventing infectious diseases . . . . No treatment permanently reverses the suppression of the immune system; no vaccine prevents infection.").
30. WASHINGTON STATE BD. OF HEALTH, supra note 4, at 1.
32. WASHINGTON STATE BD. OF HEALTH, supra note 4, at 1.
prejudice. These fears lead to feelings of isolation, depression, and a multiplicity of other psychological problems. In 1995, the AIDS epidemic reached a critical point as the number of reported AIDS cases exceeded one-half million. Today, the CDC reports the number of HIV/AIDS-infected individuals in this country to be 753,907. As the crisis continues, it is critical that states impose tracking systems in order to control and monitor the spread of the epidemic.

II. AIDS LEGISLATION

State and national governments responded to the AIDS crisis through legislative measures. In 1984, nationwide AIDS case reporting began. Reporting the names of individuals with AIDS became a major part of a national effort to understand and control the AIDS epidemic. Today, every state has statutes or regulations requiring laboratories to report the names of individuals with AIDS to health departments. AIDS surveillance is widely accepted as one of a number of tools necessary to thwart the spread of the disease.

In addition to the necessity for health services to halt the spread of AIDS, infected individuals' short period of survival is thought to outweigh any potential social risks stemming from AIDS case reporting. Additional justification stems from the fact that individuals with AIDS are already part of the health care system. The rationale is that reporting the names of people with AIDS will not have a deterrent effect on people currently receiving medical care.

Traditional AIDS surveillance focused on the most advanced stage of infection, which usually develops ten years after initial HIV

34. Howe & Jensen, supra note 18, at 7.
35. CENTER FOR DISEASE CONTROL AND PREVENTION, 12 HIV/AIDS SURVEILLANCE REP. MID-YEAR 2000 1, 6 (2000). These statistics show incidence of AIDS through June 2000. Adult and adolescent AIDS cases composed 745,103 of this total. Children under the age of 13 composed 8,804 of reported cases.
37. King County Pub. Health, supra note 2.
38. Gostin et al., supra note 21, at 1162.
39. Id. at 1163.
41. Gostin et al., supra note 21, at 1162.
42. See Sharp, supra note 40.
infection. However, due to the length of time between transmission and the manifestation of AIDS, traditional surveillance statistics revealed only a small portion of the true picture of the epidemic.\textsuperscript{43} It became obvious that, in order to truly grasp the extent of this epidemic, it was necessary to track HIV infection as well.

Advances in medical technology, such as Highly Active Anti-Retroviral Therapy (HAART), provided an additional justification for tracking HIV infections. HAART drastically changed the quality of life for people with HIV. Indeed, it brought about the very first decline in annual AIDS-related death rates since the inception of the disease.\textsuperscript{44} Thus, as the medical field gained a greater understanding of the role HIV plays in the development of AIDS, the focus of case reporting shifted from tracking the appearance of opportunistic infections to identifying immunosuppression.\textsuperscript{45}

Today, the focus of HIV reporting laws is not only persons who have full-blown AIDS, but also those who suffer from asymptomatic HIV infection.\textsuperscript{46} In general, HIV reporting requires laboratories and health officials to report new HIV infections to state health authorities. HIV surveillance focuses on the earliest stages of infection. One major advantage in identifying infected populations sooner is that health departments are then more likely to link HIV positive individuals to health services, education, and partner notification programs.\textsuperscript{47} Early tracking also provides a clearer picture of the number of people currently living with HIV, allowing officials to monitor the way in which the disease is spreading.

Despite the rationales offered in support of HIV case reporting, the issue continues to ignite political controversy.\textsuperscript{48} While AIDS reporting is widely accepted, opponents of HIV reporting assert that

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\textsuperscript{43} Gostin, supra note 21, at 1163.
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\textsuperscript{44} Anna Forbes, Special Report "Names" Versus "Unique Identifiers": The "How" of HIV Case Reporting, SIECUS REP., Feb. 1, 1998, at 3, available in WL 32496867 (explaining that, in the advent of HAART, state AIDS data does not properly illustrate the full scope of the epidemic).
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\textsuperscript{45} TEXAS DEP'T OF HEALTH, RECOMMENDATIONS ON HIV INFECTION REPORTING 1 (Jan. 1998) ("As experts gained a greater understanding of the underlying mechanisms of disease development, the AIDS case definition and focus of disease surveillance shifted from tracing diagnoses of opportunistic infections [sic] (1982 case definition) to using laboratory evidence of severe immunosuppression (CD4+ below 200 microliters per decaliter of blood) as a marker of the beginning of AIDS . . . .").
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\textsuperscript{46} Sadler, supra note 36, at 196 (explaining that during the initial period of HIV infection, individuals do not display physically apparent symptoms of disease).
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\textsuperscript{47} Gostin & Hodge, supra note 17, at 712 (arguing that a national system of HIV surveillance will provide a better understanding of the epidemic, assist in prevention, and enable better distribution of public health services).
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\textsuperscript{48} See discussion infra Parts IV & V.
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its potential for harm outweighs public health concerns. Opponents argue that fewer people will get tested due to their fear of public disclosure should they test positive for HIV.

III. PUBLIC HEALTH VERSUS CIVIL LIBERTIES

It is the duty of health authorities to take measures to protect the public health. "Treating persons already ill, providing preventative therapies for individuals who came into contact with infectious agents, investigating and halting outbreaks, and removal of harmful health exposures are key ways public health officials protect the public." Tracking systems are traditional weapons against a wide range of infectious diseases. Such systems aid prevention by linking infected persons to medical resources and counseling. Despite this, government tracking systems have always appeared suspect to civil liberties organizations and even to some medical professionals.

Because HIV is an infectious disease, public health officials assert that it must be reported in the same manner as tuberculosis and many sexually transmitted diseases. Furthermore, HIV case reporting will result in increased testing of partners, earlier treatment, and improved tracking of the epidemic. Despite these arguments in favor of including HIV within a long list of reportable conditions, HIV case reporting remains an extremely divisive issue.

Opponents of HIV case reporting put forth a number of compelling arguments against the imposition of a tracking system to control AIDS. They assert (1) that the government will misuse this sensitive data to deny insurance and employment to HIV positive persons, (2) that public knowledge of one’s HIV status will result in social stigmatization and public persecution, and (3) that case reporting will deter individuals who are at risk from getting tested and seeking medical care. The thrust behind these arguments is the same: AIDS is different. Unlike other diseases, public knowledge of one’s HIV status may be detrimental to an individual’s personal life and emotional well-being.

49. See generally Gostin & Hodge, supra note 17.
52. Id.
53. Gostin & Hodge, supra note 17, at 684-85.
IV. SOCIAL STIGMATIZATION AND DETERRENCE

As the AIDS epidemic grew, the fear of AIDS transformed into a fear of people with AIDS. The highly publicized case of Nushawn Williams, a New York resident accused of intentionally transmitting HIV to several women through unprotected intercourse, gave rise to a public perception that HIV positive individuals are sexual predators and, in some cases, criminals. Additionally, the prevalence of AIDS in the homosexual community and among intravenous drug users further increased public condemnation of victims of the disease.

The notion that AIDS is a highly contagious disease also contributes to the victimization of HIV infected persons. Most studies show, however, that AIDS is not unusually contagious, nor is it spread by casual contact. Unlike tuberculosis, which may be transmitted through the air, HIV transmission requires intimate bodily contact. Specifically, the virus is generally spread through the exchange of blood or semen, and, therefore, it is not easily transmissible.

Social stigmatization, which may result from public knowledge of an individual's HIV status, deters people from getting tested. Women whose HIV tests indicate the use of controlled substances fear losing custody of their children. Immigrant populations fear that a

55. Id. See also Jean R. Stermlight, Negligence and Intentional Torts, in AIDS AND THE LAW 347, 362-63 (David W. Webber ed., 1997) (discussing legal claims for emotional distress as a result of a fear of HIV infection and possible development of AIDS).

56. See, e.g., Lisa Holewa, Leashed Names Prompt Inquiry; AIDS Confidentiality Brought into Question, SUN-SENTINEL, Sept. 21, 1996, at 23A (discussing an incident in Florida where a list of approximately 4,000 AIDS patients was stolen and sent to two newspapers); Richard Perez-Pena, Town Finds AIDS Is No Longer Someone Else's Illness, N.Y. TIMES, Oct. 28, 1997, at B8 (discussing the case of Nushawn Williams, the Jamestown, New York resident who, despite his knowledge of his HIV-positive status, had sex with dozens of young women, infecting at least twelve of them); Iain Ith, Man Accused of Infecting Women with HIV, SEATTLE TIMES, March 21, 2000, at B1.

57. See Dunlap, supra note 54, at 910-12.

58. Sadler, supra note 36, at 209.

59. Green, supra note 29, at 33.

60. Sadler, supra note 36, at 197 (listing various modes of HIV transmission including "sexual contact . . . perinatal exposure, breast feeding, and exposure to blood or blood products, such as by transfusion or needle sharing.").

61. Green, supra note 29, at 33-35. Green states that "[HIV is] fragile and easily killed outside the body. In fact, the virus is destroyed by standard solutions of almost all common disinfectants, such as hydrogen peroxide, bleach, Lysol, or alcohol." Id. Green also discusses the difficulty of HIV transmission despite prolonged exposure. Id.


63. Id. at 867 (citing Penelope Ploughman, Public Policy Versus Private Rights: The Medical, Social, Ethical, and Legal Implications of the Testing of Newborns for HIV, 10 AIDS & PUB. POL'Y J. 182, 193 (1996)). See also Regina Montague, For This Peer Advocate, AIDS Walk Is a Giant Step, BOSTON GLOBE, June 3, 2000, at B4 (chronicling the life of Matilde Garcia, an HIV infected drug user who transmitted the virus to her baby, but radically altered her lifestyle in an
positive HIV test will result in deportation. In some cases, knowledge of a positive HIV test may incite episodes of domestic violence in an abusive relationship. Homosexual men have been denied housing solely because of the fear that they may have AIDS. Entire families have been evicted from their homes when one member is discovered to have AIDS. Work environments have turned hostile and aggressive when the knowledge of one's HIV status is revealed. Infected individuals have been terminated from employment or denied positions. HIV infected individuals have also been denied insurance coverage and suffered economic drain as a result of their illness.

Furthermore, public fear of HIV and AIDS is not merely directed at victims of the disease. This fear extends beyond the infected individual to those with whom an AIDS or an HIV victim closely associates. Children who have been exposed to HIV and AIDS are alienated from their playmates and denied access to public education, while family members find themselves ostracized and subject to violence and torment.

Due to these extensive social risks, legislation must be sensitive to the dramatic and complex set of emotions closely involved in the testing process. The decision to get tested for HIV is not a casual one. Rather, this decision takes place "within a context of anxiety,

effort to retain custody of her son).  
64. Burris, supra note 62, at 867.
65. Roger Doughty, The Confidentiality of HIV-Related Information: Responding to Resurgence of Aggressive Public Health Interventions in the AIDS Epidemic, 82 CALIF. L. REV. 111, 167-68 (1994) (noting that, especially in relationships that are abusive, knowledge of a woman's HIV status may lead her heterosexual partner to assume that the woman was infected through sexual or drug-related activities that took place outside the context of their relationship).
68. See Stephen Koepp, Living with AIDS on the Job; As Lawsuits Arise, Companies Are Giving Victims a Chance, TIME, Aug. 25, 1986, at 48 (referring to the case of Paul Cronan, a truck driver who was threatened with death after revealing his AIDS status to his coworkers at the phone company).
70. See Mark Scherzer, Insurance, in AIDS AND THE LAW 185, 191-92 (Harlon L. Dalton et al. eds., 1987) (arguing that legislative attention should be directed at insurance regulation in an effort to devise a system in which the expense of AIDS-related medical treatment is properly allocated).
72. See Myra MacPherson, The Children and the Flames of Fear; In Florida, a Family at the AIDS Flash Point, WASH. POST, Sept. 11, 1987, at B1 (describing how a Florida family had its home firebombed after the community discovered that two of the family's hemophiliac children were HIV-positive).
73. Burris, supra note 62, at 856.
stigma, subordination, and struggle in the various fields of the individual’s life activities.”

Successful legislative measures and surveillance programs recognize and account for social stigmatization and deterrence by protecting the privacy interests of infected persons. These protections should include penalties for intentional or unintentional disclosure and mechanisms for keeping the identity of patients confidential. Without such protections, the social risks involved in the testing process could be perceived as outweighing the benefit of medical care and treatment.

V. THE NATURE OF MEDICAL INFORMATION AND THE POTENTIAL FOR GOVERNMENT MISUSE

Mistrust of the government poses a significant barrier to developing successful measures to stop the spread of HIV infection. Because a person’s medical profile is an extremely private and intimate matter, many people believe that the government will misuse this sensitive medical data. Among the HIV infected population, which is partially composed of various marginal societal groups, suspicions of potential government wrongdoing are not uncommon. Gay political activist groups, who place great emphasis on the right to privacy, view the AIDS crisis as a threat to political gains and “a huge obstacle to further liberation.” Intravenous drug users, who already face marginalization due to the criminal nature of their lifestyle, are automatically mistrustful of government.

Medical professionals also consistently display discomfort with mandatory reporting schemes. Inherent in the doctor-patient relationship is an understanding that information exchanged between doctors and patients is confidential. HIV surveillance requires doctors to breach this confidential relationship, revealing the patient’s private medical information to the state.

Opponents of HIV and AIDS data collection point to several widely publicized incidents of informational misuse. For example, a county health worker in Florida brought home lists of HIV and AIDS patient names in order to determine the medical status of potential

74. Id.
75. Id. at 862.
78. Id. at 123.
79. Gostin & Hodge, supra note 17, at 684.
sexual partners. A former friend of the employee copied the lists and mailed the names of 4,000 Florida residents with HIV/AIDS to local newspapers. In Illinois, the state legislature implemented a statute authorizing the state to sift through the Illinois state registry of HIV infected persons in order to determine the HIV status of state health care workers. The statute further authorized the state to notify former patients of their potential exposure to the virus.

In light of these abuses and of the potential for stigmatization and discrimination in the event of a breach of confidentiality, opponents of case reporting suggest that the best way to prevent government misuse of information is to prohibit the collection of data. Unless there are strong safeguards against informational misuse, the result is that fewer members of at-risk populations will be tested for HIV. Deterring at-risk populations from the testing process will significantly hamper public health efforts to accurately monitor the spread of HIV infection.

VI. HIV SURVEILLANCE SYSTEMS

The tensions between civil liberties and public health concerns are deeply rooted. Nonetheless, the debate has recently shifted its focus. Because we have reached a critical level in the AIDS epidemic, many AIDS activist organizations and citizens now support state efforts to monitor the disease. It is widely recognized that in order for AIDS surveillance to be effective, it must include HIV tracking. Hence, the current debate has shifted from whether to employ HIV surveillance at all to which type of surveillance system will best serve the common good. In light of the sensitive nature of a person's HIV status, it is important to develop a program that properly addresses public health concerns as well as the concerns of infected individuals.

In 1999, the CDC released a formal report urging all states to adopt some form of HIV surveillance system. The CDC emphasized that the inclusion of HIV surveillance in current tracking

80. Craig Pittman, Mortician Guilty of Revealing AIDS List, ST. PETERSBURG TIMES, April 30, 1997, at 1B.
81. Id.
82. Doughty, supra note 65, at 134-35 (citing to ILL. STAT. ANN. ch. 410, § 325/5.5 (Smith-Hurd 1993)).
83. Id.
84. Id. at 179-80.
systems was a necessary response to advances in medical technology. Due to these medical advances and their positive effect on HIV-positive persons, the CDC asserted that AIDS surveillance alone does not accurately depict current epidemiological trends. AIDS surveillance will not properly demonstrate the need for increased care and prevention services for HIV-infected individuals. Nor will AIDS surveillance properly illustrate the dramatic rise in new infections in women, heterosexuals, and communities of color.

The CDC recommended that states adopt one of two types of reporting systems. One system reports an individual’s HIV status to state health officials using the name of the infected person. The alternative, less common system, uses a code or method of encryption so that the identity of the HIV-positive patient remains private. Both systems involve a balancing of public health concerns against the privacy interests of patients. As the main goal of any HIV surveillance system is to protect the public health, the CDC supports any state that wishes to implement an HIV surveillance program.

A. Names Reporting

Names-based HIV surveillance systems are favored by state administrative bodies because the programs are easy to implement. Because states already have names-based systems in place to monitor incidences of AIDS, imposing a similar system for HIV requires very few structural adjustments. It is inexpensive to implement and, intuitively, patient names seem to be a logical method of identification. Under this system, providers or laboratories report the names of HIV positive individuals to local and/or state health officials by patient name. Then, health officials encode this information and provide the data to the CDC.

Several justifications may be offered in support of an HIV surveillance system based on names. First, because this method involves a fairly simple process, providers are likely to comply with requests for

86. Centers for Disease Control and Prevention, supra note 85, at 1.
87. Id.
89. Id.
90. Id.
91. Id.
92. Id.
93. Forbes, supra note 44, at 3.
information and provide accurate and complete data.\textsuperscript{94} Second, names-based case reporting most accurately reflects movement in the epidemic and, thus, provides the best basis for the allocation of funds and resources.\textsuperscript{95} Third, names-based reporting ensures that those infected with HIV will be provided with complete information, care, and counseling. Finally, reporting the names of patients makes it less likely that a person will be counted more than once should she seek services at several locations.\textsuperscript{96} Thus, the integrity of data remains intact because names reporting significantly reduces the possibility of duplicate case reports.

Due to the practical need for accurate information on HIV infection, names-based reporting has earned the support of major health care authorities including the American Medical Association and the New England Journal of Medicine.\textsuperscript{97} In fact, there have been recent proposals to implement a \textit{national} system of HIV surveillance by patient name.\textsuperscript{98} It is understood that with the names of infected individuals, it is easier to link persons to health services and to the latest treatments.\textsuperscript{99} Access to patients' names allows providers to easily contact an individual if necessary.

\textbf{B. Unique Identifiers}

The alternative to a names-based system of HIV surveillance is a system that encodes the infected individual's medical and personal information.\textsuperscript{100} Such a system seeks to maintain an individual's privacy while acquiring the data necessary to track HIV infection. This type of tracking program is frequently referred to as a unique identifier system (UI) in reference to the non-name based code used for identification purposes. A UI is a numeric or alpha-based code that corresponds to a location or an individual.\textsuperscript{101} Social Security numbers and zip codes are both examples of UI codes.\textsuperscript{102}

The CDC provided both Maryland and Texas with one-time $600,000 grants to implement HIV surveillance systems using UI codes instead of names.\textsuperscript{103} Although their success rates in terms of

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\item[94.] \textit{Id.}
\item[95.] King County Bd. of Health Res. No. 98-304 (1989) (recommending that the Human Immunodeficiency Virus (HIV) be made a reportable condition in Washington State).
\item[96.] Greenwald, \textit{supra} note 88.
\item[97.] Forbes, \textit{supra} note 44, at 3.
\item[98.] Greenwald, \textit{supra} note 88.
\item[99.] \textit{Id.}
\item[100.] See Centers for Disease Control and Prevention, \textit{supra} note 85, at 9.
\item[101.] Forbes, \textit{supra} note 44, at 8.
\item[102.] \textit{Id.}
\item[103.] Forbes, \textit{supra} note 44, at 9. \textit{See also} Liza Solomon, \textit{HIV Surveillance by Non-Name}
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accuracy and implementation differed significantly, the experiences of Maryland and Texas guided the Washington State Board of Health in making its determination as to which kind of reporting system best serves public health concerns and best respects individual privacy.  

In March of 1994, Texas implemented a UI reporting system for HIV surveillance. The core functions of the Texas HIV surveillance systems were: timely connection to care and services, disease intervention, support for epidemiological investigations and research, and support for HIV case findings. These goals, however, were not realized in the Texas system under its original construction. Texas was not successful in its implementation of an HIV surveillance system based on UI codes.

Texas found that the UI system was unreliable and did not provide accurate information. The state’s system relied upon both doctors and laboratories to report pertinent patient information to county health officials for conversion into UI codes. However, many of the reports from providers and laboratories were incomplete and missing several elements, making it impossible to construct the UI. Incomplete reports were excluded from reporting and resulted in inaccurate HIV case counts. In a time span of three years, an evaluation revealed that approximately 17,839 reports were incomplete upon submittal.

Because the administration of Texas' HIV surveillance system depended entirely on complete initial reports, the entire system was undermined when participants were unable to achieve this degree of accuracy. Inaccurate reporting made it virtually impossible for providers to link patients to particular UI codes. The Texas surveil-

Based Identifier, the Maryland Experience, NASTAD HIV PREVENTION COMMUNITY PLANNING (1998); WASHINGTON STATE BD. OF HEALTH, supra note 4, at 21.

104. WASHINGTON STATE BD. OF HEALTH, supra note 4, at 21.

105. TEXAS DEP’T OF HEALTH, supra note 45, at 7 (explaining that the UI code in Texas included the individual’s last four digits of social security number; month, day and year of birth; a numeric code for sex; and a numeric code for race/ethnicity).

106. Id. at 8.

107. Id. at 9.

108. Id. (beginning in 1995, paper reports missing 3 or more elements and were ineligible for entry, eliminating an estimated 7,000 private lab reports from data).

109. Id.

110. Id.

111. Id. at 8.

112. Telephone interview with Sharon Hopkins, Senior Epidemiologist at Public Health Seattle King County (Jan. 25, 2000). Hopkins detailed the process by which Washington developed its HIV surveillance system. She described the influential roles played by both the Governor’s Advisory Council on HIV/AIDS (GACHA) and the Common Ground Group on HIV Reporting (CG). According to Hopkins, the proposal developed by CG was the system that was adopted. A key component of the Washington approach is its emphasis on maintaining local
HIV surveillance did not include any mechanism by which providers and laboratories logged the UI and patient information. This inhibited the success of the Texas system of partner notification. Doctors were unable to notify the partners of HIV positive persons because they were unable to identify the patient from an inaccurate UI code. The system was dysfunctional because it was unable to support patient referral and disease intervention services.

Due to these problems, Texas replaced the UI system with a names-based reporting system at the beginning of 1999. According to the Texas Department of Health, "Because of the limitations inherent in the system, it is unlikely that it could ever provide the information needed, no matter how many additional resources were invested in improving the system."

In 1994, Maryland began using a UI reporting system after proposals to adopt a names-based HIV reporting system were defeated in the state legislature. A key factor in Maryland's decision to implement a UI system was the potential deterrent effect of names reporting. State officials were concerned that individuals would avoid getting tested for HIV and delay treatment due to a fear of exposure should they test positive.

The Maryland UI surveillance system, which is still in existence, differs structurally from Texas' initial UI system. For example, in Maryland, providers have the sole responsibility for constructing UI codes. Providers maintain logs that link the UI to the patient's name. Once constructed and complete, the UI is forwarded to the

control over the names of HIV infected individuals. Because there were concerns that the statewide registry of names was too accessible to state legislators, names are to be reported locally to county health departments. It is the responsibility of local health officials, not providers, to encrypt the data. Names are kept for 90 days in order to ensure that the data is complete and can be properly converted into a UI.

114. Hopkins, supra note 112.
115. Id. Hopkins emphasized that by placing the burden of accurate reporting on county health departments, Washington sought to avoid the problems that plagued the Texas HIV surveillance system. In Texas, both physicians and laboratories failed to provide complete data.
116. Id.
117. Terrence Stutz, State Health Board Adopts Rules Requiring That HIV Patients' Names Be Reported, DALLAS MORNING NEWS, Nov. 21, 1998, at 36A.
118. TEXAS DEP'T OF HEALTH, supra note 45, at 21.
119. Solomon, supra note 103 (discussing two defeated legislative proposals, one in 1992 and one in 1994).
120. Id.
121. Id.
122. Id.
123. Id.
The laboratories report the UI and test result to the state health department. Although the Maryland UI HIV tracking program is structurally different from that of Texas, the state found itself similarly plagued by problems related to inaccuracy and incompleteness.

A CDC survey illustrated that both the Maryland and the Texas UI systems fell below performance standards. When compared to names-based reporting systems, the Maryland UI system was accurate approximately 50% of the time. The Texas case reporting system had a startlingly low accuracy rate of 26%.

The problems experienced in Maryland and Texas possibly resulted from the complex structure of the encryption. Because UI systems "require several independent sources of information to produce the unique coded identifier, they often suffer from incomplete or inaccurate reporting." Between 16-43% of the reports in Maryland and Texas were missing at least one piece of data necessary to construct the UI.

The viability of a reporting system depends upon its accuracy in reporting data. Although Texas abandoned attempts to perfect its UI reporting system, Maryland sought to correct the accuracy and completeness problems that plagued its program. The ACLU points to the Maryland surveillance program as an illustration of a successful UI reporting system. Since its inception, the Maryland reporting

124. Id.
125. Id.
127. Id. at 21. See also Centers for Disease Control and Prevention, Evaluation of HIV Surveillance Through the Use of Non-Name Identifiers—Maryland and Texas, 46 Morbidity & Mortality Wkly. Rep. 1254, 1255 (1998) (identifying evaluation criteria as "the proportion of reports with full UI codes, timeliness and completeness of HIV reporting, and potential for matching the UI-based case reports to alternate databases.").
129. Id.
130. Id. at 38. See also Centers for Disease Control and Prevention, supra note 127, at 1255 (explaining that Maryland and Texas both constructed the UI code using last four digits of the patient's Social Security number, date of birth, one-digit code for race/ethnicity, and one-digit code for sex).
133. Id. ("The UI program gives Maryland the data it needs to track HIV infection in the State and to guide decisions about AIDS funding and prevention efforts. Officials at the Maryland AIDS Administration are pleased that the Unique Identifier system has enjoyed considerable community support and is thought to create an environment in which individuals are more willing to be tested and learn their HIV status.").
system has improved and experienced rising accuracy rates.\textsuperscript{134} Maryland's UI completion rate is now almost 97% for state-funded sites.\textsuperscript{135} The Maryland AIDS Administration continues to promote the viability HIV tracking by UI as opposed to names.\textsuperscript{136}

The Maryland experience indicates that the implementation of a UI system is not a hopeless endeavor. Implementation of any tracking system will require a large input of time and energy before it functions at an acceptable rate of completion. Ultimately, the issue of which system is preferable depends on which approach better balances the interests of the infected against public health concerns.

\textit{C. Choosing Between the Two Programs}

The numerous factors favoring names reporting require examination. Despite arguments to the contrary, HIV surveillance by patient name will not reflect movement in the epidemic more accurately than a properly executed surveillance system based on UI code.\textsuperscript{137}

Problems of inaccuracy and duplicated case reports are not confined to UI surveillance systems. Rather, duplication also poses a problem in names-based reporting states.\textsuperscript{138} If a patient seeks treatment at more than one location, it is possible that two case reports will be generated. This type of duplication may be greatly reduced in a system that constructs a unique code for each individual who tests positive for HIV.\textsuperscript{139} Because the information used to construct a UI code is unique for each individual, there is little likelihood that duplication will occur even if the patient seeks care at multiple locations.

Proponents of names-based reporting assert that it enhances partner notification. Where cases are indexed by patient name, health officials can make numerous attempts to uncover the names of an infected person's partners.\textsuperscript{140} However, patient names are not essential

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134. Id.
135. See Greenwald, supra note 88. Greenwald notes, however, that the rate of inaccuracies are lower in private testing sites. Id.
136. See Liza Solomon & Georges Benjamin, Letter to the Editor, 338 NEW. ENG. J. MED. 626, 626 (1998) ("Given the traditional American concern about the privacy of medical records and the very real potential for discrimination against people infected with HIV, we believe that our system provides the benefits of epidemiologic monitoring of the epidemic and averts the creation of barriers to HIV testing and treatment among those concerned about confidentiality. We suggest that states considering HIV surveillance investigate non-name-based HIV-surveillance systems as an important option.").
137. Doughty, supra note 65, at 166.
138. Gostin & Hodge, supra note 47, at 737.
139. Id. at 737-38.
140. Grant Nash Colfax & Andrew B. Bindman, Health Benefits and Risks of Reporting HIV-Infected Individuals by Name, 88 AM. J. PUB. HEALTH 876, 877 n.6 (June 1998).
\end{flushleft}
to successful partner notification. In fact, partner notification is most successful when it is performed in an entirely voluntary and anonymous manner. Individuals are more apt to participate in partner notification programs if they understand their medical profile will be confidential.

From a practical standpoint, UI reporting is not a significantly more complex method of tracking HIV infection. The technology employed to encrypt patient data is not uncommon. Encryption of patient information is currently used in AIDS surveillance. Although the incidence of AIDS is reportable by name at the state level, state officials currently encrypt AIDS medical data before reporting it to the CDC. Thus, the technology to encode patient data is readily available to state health officials.

Despite the arguments in favor of names reporting, there are compelling reasons to take the alternative route and adopt a UI system of surveillance. Although HIV surveillance by UI code is a more laborious method of tracking, the increased amount of time required to encrypt patient medical information must be weighed against the privacy rights of infected individuals. Because of the extremely sensitive medical data, a system that announces the names of infected individuals is unnecessarily intrusive. Names-based HIV case reporting systems create registries in which the names of infected individuals are compiled. In the event of a breach of confidentiality, the individual's privacy interests would be violated, resulting in potentially irreparable harm.

Several organizations, including the ACLU and the National Association of People with AIDS (NAPWA), oppose names-based reporting systems. According to the ACLU, names-based reporting is not a solution to the AIDS crisis. The organization asserts that the CDC underestimates the deterrent effects of names reporting on voluntary testing. According to the ACLU, names reporting causes

141. Id.
142. See infra Part V for a discussion regarding partner notification in Washington State.
143. See Lawrence O. Gostin & James G. Hodge, Jr., Piercing the Veil of Secrecy in HIV/AIDS and Other Sexually Transmitted Diseases: Theories of Privacy and Disclosure in Partner Notification, 5 DUKE J. GENDER L. & POL'Y 9, 76 (spring 1998) (discussing studies regarding confidentiality and contact tracing).
144. Hopkins, infra note 112.
146. Id. (noting that at present time, not all states have laws that safeguard the confidentiality of HIV related information).
147. Forbes, supra note 44.
148. Id.
149. Id.
significant deterrence in those populations most affected by the AIDS crisis. In a recent response to the CDC draft guidelines, the ACLU cited numerous studies illustrating the deterrent effects of names reporting among high-risk populations.

In 1997, NAPWA issued a strong statement against the use of names in HIV surveillance. NAPWA offered fourteen criteria necessary to an effective system of HIV surveillance. Included within these criteria was data encryption. Despite the organization's zealous support of HIV surveillance, it asserted that HIV surveillance by UI code is the only tracking method that protects the patient's confidentiality and privacy. According to NAPWA, HIV surveillance systems must adapt to the changing needs of society in order to be effective. "[S]urveillance systems should be constantly re-evaluated to determine if the goal of applying surveillance data to meaningful education, programs, planning and resource allocation is happening. If not, these systems should be discontinued."

Similarly, in 1998, Gay Men's Health Crisis (GMHC) issued a position paper in which it asserted its strong belief in the benefits of HIV surveillance as a method of increasing knowledge concerning the AIDS epidemic. In its recommendations to New York State, GMHC called upon the state to evaluate the experiences of Maryland and Texas and implement a unique identifier system. Encoding information, the organization asserted, is the best possible way to ensure patients' privacy.

150. See, e.g., Centers for Disease Control and Prevention, HIV Testing Among Populations at Risk for HIV Infection—Nine States, 47 MORBIDITY & MORTALITY WKLY. REP. 1086 (1998) ("The findings indicate that in these populations' knowledge of state HIV reporting policies was low, and fear of a positive HIV test result and a lack of perceived risk for HIV infection were the most common deterrents to testing in all risk groups. However, untested men who have sex with men (MSM) who resided in states with name-based reporting cited concerns about reporting as a reason they had not tested more often than untested MSM in states without name-based reporting.").

151. See, e.g., Greenwald, supra note 88 (explaining that the 1996 Reed study conducted at anonymous and confidential sites in Los Angeles found that 86% of respondents would not seek testing if the names of those testing HIV positive were reported to government health agencies).


153. Id.

154. Id.

155. Id.

156. Id.

157. Id.


159. Id.
There is strong support and good reasons to develop HIV surveillance systems that employ unique identifiers instead of names. The deterrent effects of names-based reporting undermine the purpose of early reporting. If the purpose of a reporting system is to prevent the spread of AIDS, it certainly is not accomplished in a society that intentionally or unintentionally releases the names of those infected with HIV. "In addition, deterring people from testing means that name reporting cannot provide the most accurate, comprehensive, representative, complete, and timely data possible about the course of the epidemic." The harm that would result from the release of this information should not be underestimated. A system that takes into account the sensitive nature of an individual's HIV status will more effectively serve the common good.

VII. A CHALLENGE TO THE WASHINGTON STATE BOARD OF HEALTH

"Laws that assure confidentiality and protect people from discrimination are said to reduce resistance, while laws that require reporting of HIV test results, or other stigmatizing measures, deter testing and other behavioral changes urged by public health authorities." The challenge before the Washington State Board of Health was to create an HIV reporting system that balanced public health concerns against privacy while maintaining a level of accuracy acceptable under CDC standards. This section will describe the manner in which Washington approached this daunting task. Part A outlines the steps leading to the drafting of the Washington regulations. Part B details the various aspects of the Washington approach and how these aspects address private and public interests.

A. Drafting the Regulations

From the outset, the topic of HIV surveillance in Washington sparked a heated debate between public health officials and AIDS activist organizations. AIDS activists stressed that if a surveillance system was to be implemented, the least intrusive tracking method was necessary. AIDS organizations and community groups, which predominantly supported HIV surveillance, argued adamantly in favor of a confidential surveillance system based on UI codes. They feared

162. See generally Centers for Disease Control and Prevention, supra note 85.
that a names-based system would deter people from being tested and inhibit efforts to thwart the spread of AIDS. If people understood the government was compiling their medical data, they would avoid the testing process and delay necessary medical treatment.

Health officials, however, were not immediately responsive to the concerns of activist groups. The Texas experience cast doubt upon the viability of an HIV surveillance system based on UI codification. Health officials were convinced that only a names-based reporting system would provide the level of accuracy and dependability crucial to successful HIV surveillance.\textsuperscript{164}

It was not until 1997 that the Washington State Department of Health embarked upon a nearly two-year project to revise the state’s methods of tracking infectious diseases.\textsuperscript{165} Not surprisingly, particularly in light of recent recommendations from the CDC, the main item on the agenda was HIV surveillance. To address this issue, the Governors’ Advisory Council on HIV/AIDS (GACHA) appointed a task force to determine whether the time was right to implement HIV surveillance in Washington.\textsuperscript{166} More specifically, the task force was asked to ascertain which surveillance method, names or UI Codes, would best serve the interests of Washington State.\textsuperscript{167}

The task force was originally composed solely of GACHA members.\textsuperscript{168} However, in order obtain the broadest possible input regarding HIV surveillance, the task force was expanded to include members of AIDS organizations and citizen groups.\textsuperscript{169} A series of public forums was held and the public was invited to share its comments with the task force.\textsuperscript{170} The group met regularly to discuss the various systems available and how each alternative would work in Washington State.\textsuperscript{171}

The task force devised a list of specific objectives for a successful surveillance system.\textsuperscript{172} First, a surveillance system should aim to make the highest possible percentage of people aware of their HIV status.\textsuperscript{173} Second, such a system should help determine the movement and extent of HIV infection.\textsuperscript{174} Third, the system must connect as many

\textsuperscript{164} Id.
\textsuperscript{165} Washington State Dept. of Health, supra note 51.
\textsuperscript{166} See generally GOVERNOR'S ADVISORY COUNCIL OF HIV/AIDS, HIV REPORTING TASK FORCE REPORT (Jan. 27, 1998) [hereinafter GACHA].
\textsuperscript{167} Id. at 1.
\textsuperscript{168} Id.
\textsuperscript{169} Id.
\textsuperscript{170} Id.
\textsuperscript{171} Id.
\textsuperscript{172} Id. at 1-2.
\textsuperscript{173} Id. at 1.
\textsuperscript{174} Id. at 2.
people as possible with health care services.\textsuperscript{175} Fourth, there must be an accurate determination as to how many AIDS cases there are and thus what resources are necessary.\textsuperscript{176} Fifth, a successful HIV surveillance system must expend as few resources as possible in accomplishing these tasks.\textsuperscript{177} Additionally, the group determined that a goal of a reporting system should be to "maintain the highest levels of privacy and confidentiality for HIV+ [sic] people."\textsuperscript{178}

The task force found that AIDS surveillance in Washington, in light of advances in medical treatments, was no longer effective. The time had come to implement a system of asymptomatic HIV case reporting in Washington State.\textsuperscript{179} AIDS reporting alone was less useful because AIDS develops more than ten years after the time of initial infection.\textsuperscript{180} As a result, AIDS surveillance could not accurately reveal patterns in disease.\textsuperscript{181} The task force also found that for many at-risk individuals, the fear of public exposure and stigmatization remained a major factor behind the decision to take an HIV test.\textsuperscript{182}

GACHA performed a thorough analysis of the viability of each tracking system in addressing both public health concerns and the fears of at-risk individuals.\textsuperscript{183} Forwarding its complete findings to Governor Gary Locke for his consideration, GACHA recommended that Washington State implement an HIV surveillance system based on UI codes.\textsuperscript{184} According to GACHA, factors that mitigated in favor of names reporting included: (1) providers' familiarity with names reporting systems, (2) the traditional acceptance of names reporting as an effective method of disease surveillance, and (3) the high probability that infected individuals are properly linked with care and counseling with the names-based reporting system.\textsuperscript{185} However, GACHA found that the best way to balance public health concerns against the rights of infected persons was to impose a system of HIV surveillance based on UI codes.\textsuperscript{186}

\textsuperscript{175} Id.
\textsuperscript{176} Id.
\textsuperscript{177} Id.
\textsuperscript{178} Id.
\textsuperscript{180} Hopkins, \textit{supra} note 112.
\textsuperscript{181} Id.
\textsuperscript{182} Id.
\textsuperscript{183} See generally GACHA, \textit{supra} note 166.
\textsuperscript{184} Id. at 19.
\textsuperscript{185} Id. at 5-11.
\textsuperscript{186} Id. at 19.
The task force found that the use of UI codes in an HIV surveillance system would address patients' fears regarding the confidentiality of their medical information. "In order to help the greatest number of people learn their HIV status and access care, it is vital that public health maintain a solid and cooperative relationship with the HIV/AIDS community and those at greatest risk for HIV infection." 187

The GACHA report stressed that it was not enough to emphasize the simplicity of names reporting without balancing it against its potentially deterrent effects. 188 As suggested previously, names reporting may cause high-risk populations to avoid the testing process. 189 "This is of particular concern in Washington, where the HIV/AIDS epidemic continues to be driven primarily by gay and bisexual men." 190 In order to thwart the spread of AIDS, it is crucial that these communities are ensured access to health care and confidential medical testing.

While the GACHA task force clearly recognized the need to balance public health concerns against the rights of infected individuals, the final plan for an HIV surveillance system aimed at achieving this balance was developed at the local level. In King County, the most populated county in the state, local health officials and concerned members of the community formed a group to discuss HIV surveillance. 191 The coalition, The Common Ground Work Group (CG), agreed that the implementation of HIV surveillance was a necessary step in the fight against AIDS. 192 The divisive issue remained the proper method of surveillance. 193

CG met only a few times, but it worked diligently to come to a successful compromise. 194 The group recognized the limitations and problems inherent in both HIV tracking systems. 195 Ultimately, it found that a surveillance system based entirely upon either names or UIs would not serve the needs of the community. 196 Rather, CG recommended to the Department of Health (DOH) that Washington adopt a system of HIV surveillance that included names reporting at
the local level and the conversion of patient information into UI codes prior to reporting data to state health officials. This compromise placed the burden of compiling accurate case reports on county health officials, instead of on providers as in the Texas system, while upholding the privacy interests of patients by prohibiting the release of sensitive medical information to state government officials.

The CG recommendation proved a desirable compromise to all interested parties. On July 14, 1999, after two years of planning and debate, the DOH voted unanimously to impose a hybrid system of asymptomatic HIV case surveillance in Washington. On September 1, 1999, local health departments began reporting HIV surveillance data to the state in the form of UI codes.

B. Characteristics of the Hybrid Model

An analysis of the key aspects of the Washington regulations illustrates the state's success in setting a proper balance between public health and civil liberties. First, the names of infected individuals are recorded for only a brief period of time. Under the regulations, in the event of a positive HIV test, laboratories and providers must forward a patient's name and vital information to the local health department. Upon completion of the case record, the local health department is responsible for encrypting the name and demographic information into a UI code. Names will not be kept longer than ninety days.

This ninety-day period is an important aspect of the Washington regulations because it gives county health officials enough time to properly construct a UI code. During this period, officials have the opportunity to contact providers if there is inadequate information in the case report. Because doctors do not have the patient codes, the county health officials must be able to refer to the patient by name when seeking this necessary data. In this manner, the Washington system seeks to avoid the problems of inaccuracy and incompleteness that plagued the Texas HIV surveillance system.

197. Id.
198. Hopkins, supra note 112.
200. Hopkins, supra note 112.
202. WASH. ADMIN. CODE § 246-100-076.
203. WASH. ADMIN. CODE § 246-101-520(1)(b), (c).
204. Hopkins, supra note 112; WASH. ADMIN. CODE § 246-101-520(4).
205. Id.
206. Hopkins, supra note 112.
After the ninety-day period, the patient’s information is destroyed.207 The encoded data is then reported to state officials who provide subsequent reports to the CDC. In order to respect the privacy interests of infected persons, Washington State officials never receive a list of names of HIV-positive individuals.208 The purpose of prohibiting the release of names to state officials is to alleviate community concerns regarding privacy by preventing a centralized state registry of names. This concept is unique among the states that employ HIV surveillance by UI code.

Second, as a means of encouraging voluntary HIV testing, the Regulations provide both confidential and anonymous testing options.209 Both the CDC and the Washington State Board of Health recognize the importance of anonymous testing as a method of encouraging HIV testing.210 Under the regulations, persons considering testing will be provided with the option to test confidentially or in an anonymous manner.211 Should an individual chose the confidential option, her name will be protected by the UI system. Where an individual opts to test anonymously, her information will not be reported anywhere.212

Anonymous testing ensures that the identity of the individual will not be linked to the result of the test.213 Public locations that perform anonymous HIV tests are available in every region of Washington.214 A person may also elect to test anonymously by using a home testing kit.215 However, once an individual seeks treatment for HIV, a case report will be generated and subsequently forwarded to county health officials.216

Confidential testing is different from anonymous testing in that the individual will be linked to the test results. For example, in the context of HIV surveillance, “confidential” means that a person’s information will be kept private. In other words, the identity of the infected person will be reported, but in a private manner and only to designated public health officials. After a 90-day period, the patient’s

207. WASH. ADMIN. CODE §§ 246-101-520(1)(b). See also WASH. ADMIN. CODE § 246-100-072 (regarding destruction of information related to identified partners).

208. WASH. ADMIN. CODE § 246-101-520(4).

209. WASH. ADMIN. CODE §§ 246-100-209, 246-100-206.

210. WASHINGTON STATE Bd. OF HEALTH, supra note 4, at 22.

211. WASH. ADMIN. CODE § 246-100-209.

212. WASH. ADMIN. CODE § 246-100-206(1)(a).

213. Id.

214. WASH. ADMIN. CODE § 246-100-209(1)(c)(i).

215. Id.

216. WASH. ADMIN. CODE § 246-100-206(1)(a).
name is expunged and the case report is destroyed.217 Any potential misgivings about the integrity of such a system may be alleviated due to the fact that it is not possible to convert the codes back into names. Hence, the patient’s identity receives the maximum degree of protection under the regulations.

Third, the regulations provide safeguards against government misuse of information.218 Access to the data is limited to local health officials who are required to sign periodic confidentiality agreements.219 Breaches of confidentiality are subject to both criminal and civil penalties.220 Any breaches must be reported to state officers and are subject to investigation and penalty by both state and local health officials. The CDC assists state health departments in any investigatory processes and recommends security improvements where necessary.221 Recent laws increase the penalties for improper disclosure of medical and related health information by making violations gross misdemeanors as punishable by one year in prison and civil fines of up to $10,000.222

Fourth, partner notification, a key element to the success of any HIV surveillance system, is provided in a manner that maintains the individual’s privacy interests by restricting notification to situations where both the patient and the provider consent to the use of this service.223 Because infected individuals “may be members of socially-disfavored [sic] groups such as sex workers, injection drug users, or gays, partner notification is a particularly sensitive issue. Disclosure of one’s HIV status can result in social stigma among their family and friends.”224 Among socially disfavored groups, the danger of any potential social risk may outweigh the benefit of medical knowledge.

217. WASH. ADMIN. CODE § 246-101-520(1)(b). See also WASH. ADMIN. CODE § 246-100-072(5)(c) (mandating that any information related to partners also be destroyed).
218. Hopkins, supra note 112. While several pieces of personal data are necessary to create a UI code, the codes cannot be analyzed to reveal a patient’s name. The unique manner in which the information is codified enables local health departments to determine if the individual’s data has been previously recorded, thereby eliminating the possibility of duplicate case reports.
219. WASH. ADMIN. CODE § 246-101-520(5).
220. Id. See also WASH. REV. CODE § 70.24.105.
221. Centers for Disease Control and Prevention, supra note 85, at 10; WASH. ADMIN. CODE § 246-101-520(6).
222. RCW 70.24.022; RCW 9A.20.021 (increasing penalties for unauthorized disclosure of HIV data reports and other STD reports); WASH. ADMIN. CODE § 246-101-520(5).
224. Gostin & Hodge, supra note 17, at 679.
The Washington regulations take into account the perception of this social risk. The regulations allow for notification only where the patient voluntarily consents to this process. An HIV-positive person has the option to personally inform her sexual or needle-sharing partners of her HIV status but may otherwise request the assistance of her provider. Partner notification is the responsibility of the doctor, but the doctor may request assistance from the local health department when performing this task.

Because partner notification involves complex issues of privacy and social consequences, the names of the HIV infected individual are not revealed to partners absent written patient consent. Rather, the provider or local health personnel recommends to the partners that he or she be tested for HIV.

VIII. CONCLUSION

Monitoring AIDS alone no longer serves the common goal of thwarting the spread of AIDS. New advances in medical technology and therapy have proven to be successful methods of keeping HIV-infected individuals alive longer. Today, HIV-positive people live healthier and more productive lives. In order to properly understand the extent of the epidemic and utilize our resources in the most efficient manner, surveillance must be expanded to include HIV infections. Moreover, HIV surveillance will link HIV-positive people to vital medical services.

In light of the sensitivity of AIDS-related information and the harmful effects of improper disclosure, the best method of surveillance is achieved through the use of UI codes. Names-based reporting systems do not provide adequate safeguards and may deter high-risk groups from the testing process.

The Washington State regulations illustrate the proper balance between public health and civil liberties. The new regulations are advantageous in a number of ways. They promote privacy and confidentiality in a manner that does not adversely affect the integrity of the data. They promote AIDS awareness and encourage a sensitive and informed response to issues involving HIV and AIDS. They provide safeguards against informational misuse and confidentiality problems. The unique codification procedure greatly reduces the possibility of duplicate or inaccurate case reports. Because UI codes

225. WASH. ADMIN. CODE § 246-100-072.
227. WASH. ADMIN. CODE § 246-100-072; WASH. REV. CODE § 70.24.105.
228. WASH. ADMIN. CODE § 246-100-072; WASH. REV. CODE § 70.24.105.
cannot be linked to the patient source, fears of social stigmatization are alleviated. Most notably, HIV surveillance by UI code will not deter people from the testing process and, therefore, may inhibit the spread of HIV among those who would otherwise remain ignorant of their HIV status.