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# HIV Reporting in California: By Name or by Number?

By Nicole Kamm\*

## I. INTRODUCTION

In California, 5,903 AIDS cases were recorded in 2003, making for a cumulative total of 133,292 since the implementation of nationwide mandatory AIDS case reporting.<sup>1</sup> There are no comparable statistics for the number of HIV cases in the state because California currently uses a code-based system called Unique Identifier (UI) reporting.<sup>2</sup> Under this model, patients' names are partially codified by health care providers who transfer the information to local health officials.<sup>3</sup> The local health department completes the encryption and releases the data to state officials, who are then responsible for reporting to the Centers for Disease Control and Prevention (CDC).<sup>4</sup> This process is intended to prevent the identity of HIV-infected individuals from being released to federal authorities because release of names is limited to the local level.

In 2004, the Los Angeles County Commission on HIV Health Services ("Commission") issued a proposal in support of replacing the current UI surveillance system with name-based HIV reporting, in both Los Angeles County and statewide.<sup>5</sup> The Commission supported

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1. See <http://www.cdc.gov/hiv/stats.htm#area> (last visited on Feb. 2, 2005).

2. See <http://www.statehealthfacts.org> (last visited on Feb. 2, 2005).

3. See *infra* Part III.b.1.

4. See *infra* Part III.b.1.

5. Los Angeles County Commission on HIV Health Services, Policy Paper Supporting State and Local Name-based Surveillance Systems at 1 [hereinafter

this submission as a public health measure, in consideration of allocation of federal funds, and with the understanding that the civil rights concerns previously raised by name-based reporting systems “have declined over the years.”<sup>6</sup> Despite an undercurrent of opposition, the Commission’s proposal was approved in October 2004, and its representatives will proceed to advocate adoption of name-based HIV reporting to the Los Angeles County Board of Supervisors and the governor of the State of California.<sup>7</sup>

This comment examines the legal and policy considerations surrounding HIV reporting systems. Specifically, it focuses on the current controversy over California’s HIV surveillance system. Part II details the historical development of disease reporting, as well as briefly describing the inception of the AIDS epidemic. Part III examines the two most common HIV reporting systems, name-based and UI reporting, and compares anonymous testing. Part IV reviews the constitutional issues raised by HIV reporting systems. Part V concludes the comment.

## II. HISTORICAL BACKGROUND

### A. History of Disease Reporting

The basis for all public health initiatives is the “collection, analysis, and interpretation” of information regarding the health of a

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Commission Paper on HIV Health Services]. The Commission serves as the state’s planning body for Title I of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and all other publicly funded HIV services programs managed by the Office of AIDS Programs and Policy (OAPP). See <http://www.lapublichealth.org/aids/archives.html> (last visited on Sept. 26, 2004). The Commission’s mission is “to decrease HIV/AIDS mortality and morbidity by improving the quality and availability of comprehensive HIV/AIDS-related services to needy individuals and families.” *Id.* For more information about the Ryan White CARE Act, see *infra* note 186 and accompanying text.

6. Commission Paper on HIV Health Services, *supra* note 5.

7. *Id.* In support of the Commission’s objective, see 4 CALIFORNIA PERFORMANCE REVIEW REPORT: ISSUES AND RECOMMENDATIONS chap 2, § HHS 14, *Make California’s HIV Reporting System Consistent With its AIDS Reporting System and improve AIDS Reporting* (2004), available at <http://cpr.ca.gov/report/cprprt/issrec/hhs/hhs14.html> (last visited on February 2, 2005) [hereinafter California Performance Review].

specific population.<sup>8</sup> The first known example of disease surveillance in the United States dates from a 1741 Rhode Island statute requiring tavern owners to inform local health authorities about customers who had contracted contagious diseases.<sup>9</sup> Later, Rhode Island passed similar legislation mandating the reporting of such diseases as cholera, yellow fever, and small pox.<sup>10</sup>

In 1850, a report linking substandard living conditions and disease was submitted to the Massachusetts Sanitary Commission.<sup>11</sup> In connection with the report, state-supported reporting of health data “by age, gender, occupation, socioeconomic level and locality” was urged.<sup>12</sup> Possibly influenced by England and Wales, the federal government also began publishing nationwide data on mortality at that time.<sup>13</sup> Increased reliance on and improvement of mortality data

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8. See Lawrence O. Gostin and James G. Hodge, Jr., *The “Names Debate”: the Case for National HIV Reporting in the United States*, 61 ALB. L. REV. 679, available at <http://academic.udayton.edu/health/syllabi/Bioterrorism/5DiseaseReport/PHLaw11.htm> (last visited on Sept. 26, 2004).

9. See Lawrence O. Gostin, et. al., *The Public Health Information Infrastructure: A National Review of the Law on Health Information Privacy*, 275 JAMA 1921 (1996).

The primary goal of surveillance is to track the course of a disease in a population. The objectives of surveillance are, in this sense, clearly population-based. Individuals are studied only to gather data that can then be aggregated at the population level. A key secondary goal of surveillance is to make possible a variety of prevention and control measures.

Mira Johri, et. al., *New Approaches to HIV Surveillance: Means and Ends, A Summary Report of the Law, Policy and Ethics Conference on HIV Surveillance* (CIRA Working Paper Vol. II.2, available at [http://cira.med.yale.edu/law\\_policy\\_ethics/workpapervol2iss2.html](http://cira.med.yale.edu/law_policy_ethics/workpapervol2iss2.html) (last visited on Oct. 17, 2005)).

10. See Gostin, *supra* note 8.

11. *Id.* at 690.

12. *Id.*

13. *Id.* 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.* Farr noted mortality surveillance “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.” *Id.* at 691.

led to more organized public health departments.<sup>14</sup> Reporting expanded from purely death statistics to the detection and prevention of diseases.<sup>15</sup>

By the early twentieth century, the federal government required all states to report all common contagious diseases “dangerous to the public health.”<sup>16</sup> In 1925, in response to confusion created by differing state surveillance techniques, states were required to submit uniform reports on the occurrence of infectious diseases to the United States Public Health System.<sup>17</sup> The reports, however, revealed an emerging conflict between public health officials’ duty to prevent the spread of disease throughout society and a physician’s responsibility to honor the doctor-patient privilege of non-disclosure of personal and sensitive health information.

Public health officials typically understand their duty as in response to the greater good of the population.<sup>18</sup> In contrast, physicians perceive their duty foremost to the individual patient.<sup>19</sup> Mandatory reporting requirements, while not without ultimate benefit to the patient, conflict with physician obligations under the Hippocratic Oath.<sup>20</sup> Physicians also feared the legal consequences of breaching patient confidentiality or being found liable for invasion of privacy.<sup>21</sup> Over time, the courts established a framework within which physicians were relieved of excessive liability from such claims while adhering to reporting requirements.<sup>22</sup> By the 1960’s, it became clear that the public need to stop the spread of communicable diseases outweighed individual interests in the majority of

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14. *See id.* at 690.

15. *Id.*

16. *Id.* at 692.

17. *Id.* at 692-93.

18. *Id.* at 693.

19. *Id.* at 693-94.

20. *Id.* at 694. In addition to other promises, the Hippocratic Oath is an ancient ethical promise to “preserve a patient’s health information.” *Id.* Once sworn, a doctor may be liable if such information is disclosed without the consent of the patient. *Id.*

21. *Id.*

22. *Id.* at 694-95. Consider the general standard-of-care rule that a doctor’s conduct must not fall below that of the average reasonable doctor in a comparable situation.

circumstances.<sup>23</sup> Today, reporting medical information to state and federal health officials is routine practice.

### B. *The AIDS Epidemic*

The first AIDS cases were reported in the United States in 1981.<sup>24</sup> AIDS is a disease caused by HIV, a virus that progressively destroys the body's ability to fight infection by impairing the immune system's cells.<sup>25</sup> From its initial documentation in 1981, the number of AIDS cases rose steadily, largely during the early stages in the urban centers of New York, Los Angeles, Miami, and San Francisco.<sup>26</sup> In 2003, the Center for Disease Control (CDC) estimated a cumulative 929,985 AIDS cases in the United States.<sup>27</sup>

When first infected with HIV, many individuals do not develop symptoms; however, some experience a flu-like illness within the first few months of exposure.<sup>28</sup> More severe symptoms may not develop for years, but HIV destroys the immune system's cells, detectable by the decline in the blood levels of CD4+ T-cells during this period.<sup>29</sup> The first laboratory test for HIV was developed in 1985 and some states began making cases of HIV reportable by name the following year.<sup>30</sup>

AIDS refers to the most advanced stages of HIV infection.<sup>31</sup> In 1993, the CDC, the agency responsible for tracking the spread of the

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23. *Id.* at 695.

24. See AEGIS: AIDS Education Global Information System [hereinafter AEGIS], available at <http://www.aegis.com> (last visited on February 2, 2005).

25. See *id.*

26. See June E. Osborn, *The AIDS Epidemic: Discovery of a New Disease*, in AIDS AND THE LAW: A GUIDE FOR THE PUBLIC 25-26 (Harlon L. Dalton, et al. eds., 1987).

27. Statistics available at <http://www.cdc.gov/hiv/stats.htm#aidscases> (last visited on Oct. 6, 2004).

28. See AEGIS, *supra* note 24. Symptoms may include fever, headache, enlarged lymph nodes, and fatigue. *Id.*

29. See *id.* The duration of this period varies considerably from person to person. *Id.*

30. Gordon Bunch and Douglas Frye HIV Epidemiology Program, *HIV Reporting in Los Angeles County*, <http://www.ladhs.org/hiv> (last visited on February 2, 2005) [hereinafter HIV Reporting in L.A. County].

31. See AEGIS, *supra* note 24.

disease and developing the official criteria for its diagnosis, revised its definition of AIDS to include all persons who are HIV-positive and who have fewer than 200 CD4+ T cells.<sup>32</sup> In addition, the definition includes a list of twenty-six “opportunistic infections” that affect people with advanced HIV infection.<sup>33</sup> Most of these conditions are not ordinarily life-threatening to healthy individuals, but may be fatal to people with AIDS because their immune systems have been severely weakened and cannot fight off bacteria and viruses.<sup>34</sup>

In 1995, the AIDS epidemic reached critical mass as the number of reported cases exceeded one-half million.<sup>35</sup> Today, the CDC reports the number of AIDS infected individuals in the United States to be nearing one million and an estimated 850,000-950,000 people living with HIV, including between 18,000 and 28,000 that do not know they are infected.<sup>36</sup> Though the rate at which the disease is transmitted has slowed, the continuing rise in number of infected individuals indicates the crisis is not over and the need to monitor and control the spread of the disease persists.

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32. *See id.* Healthy adults generally have CD4+ T-cells counts of 1000 or more. *Id.* Individuals who have been infected with HIV may experience dramatic drops in cell count or may experience a gradual decline in the number of these cells. *Id.*

33. *See id.* The CDC list of opportunistic infections includes pneumocystis pneumonia, invasive cervical cancer, HIV encephalopathy, chronic isosporiasis, and wasting syndrome, among others. Outside of the United States, most countries use one of the two AIDS case definitions promulgated by the World Health Organization (WHO). HIV/AIDS Surveillance and Reporting in the United States, <http://www.hivinsite.ucsf.edu> (last visited on February 2, 2005). The first is recommended in cases where there is limited access to HIV antibody testing and defines AIDS as having at least two of the “major signs” and at least one of the “minor signs” of the disease. *Id.* at 3. Major signs include drastic weight loss or chronic diarrhea or fever persistent for more than one month. *Id.* Minor signs include cough for over one month or chronic herpes infection. *Id.* If HIV antibody testing is more readily available, WHO defines the disease as testing positive for HIV, as well as suffering from at least one of the various conditions from a list similar to the CDC’s list of “opportunistic infections.” *Id.*

34. *See* AEGIS, *supra* note 24.

35. *See* <http://www.cdc.gov/nchs/faststats/aids-hiv.html> (last visited on February 2, 2005).

36. *See id.*

### III. HIV/AIDS SURVEILLANCE SYSTEMS

In response to the epidemic, state and federal governments began to create legislation intended to monitor the spread of AIDS. In 1983, AIDS was added to California's list of reportable diseases and conditions.<sup>37</sup> The following year, nationwide confidential name-based AIDS reporting began.<sup>38</sup> By this measure, patient names are reported to local and state health departments and stored in registries for ongoing surveillance.<sup>39</sup> Reporting of the names of persons with AIDS is essential to understanding and controlling the epidemic and has served as "the backbone" of treatment and prevention strategies.<sup>40</sup> AIDS surveillance is widely accepted today as a requisite method for halting the spread of the disease.<sup>41</sup>

However, by advances in detection and therapy for HIV, most notably through the highly active antiretroviral therapy (HAART), persons with HIV infection are living longer without progressing to the CDC's clinical definition of AIDS.<sup>42</sup> In 1996, the incidence of both deaths and opportunistic infections caused by AIDS dropped in the United States for the first time in the history of the epidemic.<sup>43</sup> As

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37. HIV Reporting in L.A. County, *supra* note 30. In 1981, the first AIDS cases were reported by name to federal public health officials to investigate the disease outbreak. *Id.*

38. HIV/AIDS Surveillance Technical Report: Commentary, No. 1, *available at* <http://www.cdc.gov/hiv/stats/hastr1100/commentary.html> (last visited on Sept. 26, 2004).

39. *Id.*

40. *Id.*

41. Local health departments identify between ninety-five and ninety-eight percent of California's AIDS cases through name-based reporting, seeking case information from health care providers. This data is then forwarded to the state's HIV/AIDS Case Registry. California Performance Review, *supra* note 7. State health officials then verify the accuracy and completeness of the data and then pass along the information to the CDC via a secure, electronic data system. *Id.* California's AIDS reporting system is "confidential" in that only authorized personnel have access to the patient's names, which are protected with security systems at all levels. *Id.*

42. *See supra* notes 32-33 and accompanying text.

43. Johri et al., *supra* note 9 at 1. That same year, deaths due to AIDS decreased 23 percent in the general population. *Id.* Certain sub-groups, such as homosexual and bisexual men with a thirty percent observed, had an even greater decline. *Id.*



a result, AIDS surveillance systems no longer reflected an accurate or complete picture of HIV in the United States.<sup>44</sup> AIDS surveillance systems focus mainly on the most advanced stage of HIV that, without effective treatment, develops on average about ten years after initial infection.<sup>45</sup> Surveillance of the end-stages of HIV started to be recognized as “inadequate in accurately portraying how HIV infection is developing and spreading, and hence faulty as a basis for designing effective medical and public health interventions.”<sup>46</sup>

In 1999, the CDC released a formal report recommending all states conduct HIV case surveillance in addition to their current AIDS surveillance system.<sup>47</sup> The CDC noted HIV surveillance was a necessary response to the changing face of the disease and that AIDS surveillance alone did not properly demonstrate the need for increased care and prevention services for those infected with HIV.<sup>48</sup> Further, AIDS surveillance did not indicate the dramatic rise in new HIV infections in women, heterosexuals, or people of color.<sup>49</sup>

In its report, the CDC reviewed a variety of studies on two alternative HIV surveillance systems: name-based and unique identifier reporting.<sup>50</sup> The first system reports an individual’s HIV status to the state health agency using the person’s name.<sup>51</sup> The second uses a code, or unique identifier, thereby keeping the identity

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44. Though AIDS surveillance is often touted as the “gold standard” for disease surveillance, it is also recognized as an incomplete representation of the epidemic in this country because it only reports “full-blown” AIDS cases. HIV/AIDS Surveillance and Reporting in the United States, HIV In Site, *available at* <http://www.hivinsite.ucsf.edu> (last visited on Oct. 25, 2004). These statistics do not include information about new infections, which is invaluable to prevention planning. *Id.*

45. Johri et al. *supra* note 9, at 1.

46. *Id.* at 1-2.

47. Centers for Disease Control and Prevention, *CDC Guidelines for National Human Immunodeficiency Virus Case Surveillance*, 48 MORBIDITY & MORTALITY WKLY. REP. 13 (1999).

48. *Id.*

49. *Id.*

50. HIV Reporting in L.A. County, *supra*, note 30, at slide 8.

51. See generally Stacey D. Blayer, *But Names Will Never Hurt Me: HIV Surveillance & Mandatory Reporting*, 39 B.C. L. REV. 1175, 1186-89.

of the patient confidential.<sup>52</sup> The CDC requested that states evaluate the importance of surveillance data, as well as balance public health concerns against the need to protect patients' privacy interests in choosing a reporting system.<sup>53</sup> However, the CDC concluded by advising state and local surveillance programs "to use the same confidential name-based approach for HIV surveillance as is currently used for AIDS surveillance nationwide."<sup>54</sup> Despite this recommendation, the CDC noted some states have adopted the code-based unique identifier system and technical assistance will be provided by the agency regardless of which system a state decides to use.

The CDC's proposal caused controversy. AIDS reporting had gained wide acceptance, both by public and private factors, based mainly on the relatively short length of patients' survival and the obvious need to establish links to health and support services. HIV reporting, on the other hand, spurred loud opposition, largely in response to the perceived potential for discrimination and violations of privacy.<sup>55</sup> The debate divided those who supported HIV reporting by name and those who favored the alternative system of anonymous reporting by code.

#### A. Name-based HIV Reporting

In name-based HIV reporting systems, the name of the individual being tested is attached to their blood samples, which are typically sent out to laboratories for testing.<sup>56</sup> If the result of the test is positive for HIV, the lab reports the name of the individual to the state health department.<sup>57</sup> The state health department enters the name into an

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52. *Id.* "Confidential" reporting refers to a system where a person's name is "confidentially" reported to public health authorities, as opposed to "anonymous" testing where the person being tested never provides this identification and no name is sent to authorities. *Id.* The CDC called name-based reporting the "simplest, most reliable and feasible method currently available." Charles Ornstein, *California Officials Track New HIV Cases*, L.A. TIMES, July 1, 2002, at A1.

53. HIV/AIDS Surveillance Technical Report, *supra* note 38, at 8.

54. *Id.*

55. Johri et al., *supra* note 9, at 2.

56. See AEGIS, *supra* note 24.

57. See *id.*

HIV registry and then transfers the data to the CDC.<sup>58</sup> Since all states already have name-based AIDS reporting systems in place, implementing a similar system for HIV reporting would require little alteration.

There are several arguments in support of name-based HIV reporting. First, name-based reporting is the “standard method” for reporting all other reportable diseases and is based on “sound public health policy proven effective over time.”<sup>59</sup> Second, name-based reporting is less expensive and more efficient.<sup>60</sup> Finally, failure to report accurate rates of HIV cases will lead to reduced funding.<sup>61</sup> Name-based HIV reporting has received the support of most major health care authorities and among public health communities.<sup>62</sup> It arguably provides greater uniformity across the country,<sup>63</sup> makes it

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58. *See id.*

59. Commission Paper on HIV Health Services, *supra* note 5, at 2. The Commission notes that names are reported only to the state and HIV and AIDS cases sent to the CDC are only identified by code, and that all other personal identifying information is removed. *Id.* at 2. There is less potential risk of identity disclosure because names are kept in a single registry, rather than in multiple logs as under the UI system. *Id.* Finally, incomplete or incorrect UI codes are common, time-consuming to correct and may result in multiple reporting of a single individual. *Id.* at 3. Reliable, accurate information is critical for effective public health. *Id.*

60. *Id.* at 2. The unique identifier system requires both a lab report and a provider report. *Id.* It is often difficult to reconcile the lab work with the individual’s medical record. *Id.* There is more room for error when more parties are involved and the regulations are more complex to comply with. *Id.* Furthermore, the individual must reveal much of the same identifying information as in name-based reporting in order to create the unique identifier. *Id.* at 3.

61. *Id.* at 5. The Commission notes this is especially true regarding the Ryan White CARE Act and in allocation of Housing for People with AIDS (HOPWA) and Title III funds. *See* discussion *infra* Part V.a.1. Funding reductions will occur because incomplete sets of data will not be, or will only partially be accepted by funding sources, while jurisdictions that use name-based HIV reporting systems will have more accurate data, collected more easily, therefore benefit by greater allocation of funds. Commission Paper on HIV Health Services, *supra* note 5, at 5.

62. *Id.*

63. Thirty-six states use name-based HIV reporting systems, five states use name-to-code identifier systems (initially names are collected and, after any necessary public health follow-up, those names are converted to codes by the provider and the information is transferred to the state), two allow client choice of name or code and seven (including California) use a code-only system. Texas,

easier to link individuals to public health services and treatments,<sup>64</sup> and allows providers to more easily follow-up with patients should the need arise.<sup>65</sup>

Opponents of name-based reporting point out that it may dissuade individuals from seeking testing, which will ultimately reduce the overall accuracy of the data by limiting the completeness of the population sample.<sup>66</sup> Of note, often members of marginalized groups are more fearful of invasions of privacy, discrimination, or of government in general, and therefore are more likely to be discouraged from seeking testing.<sup>67</sup> Risk information is necessary in research and to develop social services, but a determined effort to collect good, complete information will not depend on name-based reporting. As to the argument that name-based reporting facilitates linkage to care for people infected with HIV, studies show most state health departments lack the resources, personnel, or intent to provide access to care.<sup>68</sup> Further, states have not historically used the AIDS registry, compiled from state AIDS cases federally mandated to be reported by name, to ensure patients' access to therapeutic interventions and follow-up care.<sup>69</sup> There is apparently no guarantee name-based reporting will result in improved linkages to care. Rather, new programs will have to be developed to ensure a connection between HIV infected persons and health care.

### *B. Unique Identifier HIV Reporting*

Unique identifier HIV reporting is the alternative to name-based systems. The unique identifier (UI) system creates a code from the

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Puerto Rico, and Kentucky used the unique identifier system and have since changed to name-based HIV reporting. California Performance Report, *supra* note 7, at 2.

64. *Id.*

65. Commission Paper on HIV Health Services, *supra* note 5, at 5.

66. Johri et al., *supra* note 9, at 6.

67. See *infra* note 205 and accompanying text. In response to this argument, the CDC recommended each state continue to offer anonymous testing. Johri et al., *supra* note 9, at 6. However, to the extent this alternative is more frequently used by certain sub-groups, the sample population will remain incomplete because the data is not reported.

68. Johri et al., *supra* note 9, at 6.

69. *Id.*

individual's personal and medical information, the purpose of which is to associate the code with the HIV test result, rather than the identity of the individual.<sup>70</sup> Numbers and letters are assembled to create an identifier that provides data about HIV infection, as well as other demographic information.<sup>71</sup> Meanwhile, the identity of the individual remains protected because, in theory, the code should not be able to be linked to their test results.<sup>72</sup>

In the early days of HIV surveillance, concern about name-based reporting led Maryland and Texas to implement a system using code-based identifiers.<sup>73</sup> Both states implemented a twelve digit numeric UI code, formed by the last four digits of a patients' social security number, six digit date of birth, one digit code for race/ethnicity, and one digit code for sex.<sup>74</sup> The use of UIs allowed for the collection and storage of data that was virtually unidentifiable. Under this system, HIV infection reports submitted to state health officials contained residence data, information about the testing facility, and the date of test, but did not include mode of transmission, which is included in most name-based reports.<sup>75</sup> To promote follow-up, health care

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70. See AEGIS, *supra* note 24. Other examples of UIs are social security numbers, bank account numbers, and driver's license numbers. However, these examples may lend support to arguments against this method of surveillance as a means to maintain anonymity. When the social security number was implemented in 1936, the federal government assured its citizens that the numbers would only be used for Social Security purposes and would remain strictly confidential. Catherine Hanssens, *Comments on the CDC's "Draft Guidelines for HIV Case Surveillance, Including Monitoring HIV Infection and AIDS"* (Jan. 11, 1999), <http://www.lambdalegal.org/cgi-bin/iowa/news/resources.html.record360> (last visited Sept. 15, 2005). Today, however, the social security number is used for numerous identification purposes, lending itself to frequent cases of fraud and invasion of privacy. *Id.*

71. See AEGIS, *supra* note 24. Sometimes codes may include symbols or numbers that represent gender, age, or ethnicity. *Id.*

72. See *id.*

73. Evaluation of HIV Case Surveillance Through Non-Name Unique Identifiers – Maryland and Texas 1994-1996, CENTERS FOR DISEASE CONTROL & PREVENTION WEEKLY (January 9, 1998), <http://www.cdc.gov/mmwr/preview/mmwrhtml/00050807.htm> (last visited on Oct. 25, 2004).

74. *Id.*

75. *Id.*

providers were required to maintain a log linking the UI to the patient.<sup>76</sup>

In response, the CDC expressed several concerns about the UI systems. They found name-based surveillance was more complete and better able to document risk factors, that the UI system created an administrative burden, and that it had the potential for duplication of cases or mismatched reports.<sup>77</sup> However, upon review three years later, the CDC found the system had substantially improved and current data “showed high levels of uniqueness for the UI, a high degree of completeness of UI elements, and a greater completion of reporting.”<sup>78</sup> In response, public health officials were “satisfied with the degree of accuracy of these data” and civil rights activists felt the UI system was “advantageous in mitigating the potential for invasion of privacy and discrimination, and hence unlikely to discourage people from seeking testing.”<sup>79</sup>

An additional concern about UI HIV reporting is the appropriateness of the system for areas of the country where there are large populations of people who may not have social security numbers, for example, through illegal immigration. In these areas, the method for creating UIs should be tailored to the community. Maryland has created a provision for those without or unwilling to disclose a social security number that inserts a “dummy 9999” code.<sup>80</sup> The state concedes this may compromise the data to some extent, but the resulting drawbacks are considerably less than name-based reporting, where many might avoid testing altogether.<sup>81</sup> The true problems, Maryland points out, with surveillance of illegal immigrants are present despite the system of HIV reporting adopted.<sup>82</sup>

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76. *Id.* Regarding reservations over the issues of patient follow-up and collection of risk data, it has been conceded that name-based reporting has advantages in terms of follow-up. Johri et al., *supra* note 9, at 8. However, collection of risk data appears to be about “average” in states with code-based HIV reporting systems. *Id.* Many states with name-based systems are less efficient at follow-up than states like Maryland, who employ a UI surveillance system. *Id.*

77. Johri et al., *supra* note 9, at 8.

78. *Id.*

79. *Id.*

80. *Id.*

81. *Id.*

82. *Id.*

A final consideration is that individuals may be confused between confidential testing, under which both name-based and code-based HIV reporting systems fall, and anonymous testing.<sup>83</sup> Many who undergo testing in states with UI systems may not understand that the identifier can be re-linked to the individual records, based on the case report to the state.<sup>84</sup> This can be addressed by requiring health care providers to consult patients before testing and anonymous testing should remain an option, even in states with unique identifier systems.

### 1. California's System

California's UI HIV reporting surveillance system became effective on July 1, 2002.<sup>85</sup> Since that date, local health departments have reported 29,970 HIV cases to the state.<sup>86</sup> State and local staffs continue to train and provide technical assistance to health care providers and laboratories to ensure the resulting data is as accurate as possible.<sup>87</sup>

Specifically, California's code-based process works in the following manner: First, along with the blood sample sent to the lab for testing, the health care provider attaches the patient's last name, date of birth, gender, date blood was collected, and name, address, and phone number of provider and facility where services were

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83. See discussion *infra* Part III.c.

84. See discussion *infra* Part III.b.1.

85. Dept. of Health Services: Office of AIDS, *HIV Non-Name Code Reporting in California, HIV Update: March 2004* <http://www.dhs.ca.gov/ps/ooa/HIVReporting/pdf/HQU.pdf> (last visited on February 2, 2005) [hereinafter HIV Non-Name Code Reporting]. California was one of the last states to implement an HIV surveillance system, due in large part to disagreement between public health officials and civil liberty advocates. Ornstein, *supra* note 52, at A3.

86. HIV Non-Name Code Reporting, *supra* note 85, at 1.

87. *Id.* A San Francisco Department of Public Health study evaluating the accuracy of California's UI HIV reporting system found results were properly matched to patients ninety-five percent of the time and complete records were produced eighty-nine percent of the time, concluding a "non-name-based laboratory reporting system for HIV is feasible." San Francisco Dept. of Public Health, *Evaluation of a Non-Name-based HIV Reporting System in San Francisco*, <http://www.ncbi.nlm.nih.gov> (last visited on February 2, 2005).

rendered.<sup>88</sup> The lab returns the confirmed HIV test result and a “partial code,” including the date of birth and gender, to the health care provider.<sup>89</sup> The lab also reports the partial code, as well as the date the specimen was tested, the name, address, and phone number of both the lab and the provider, the results of the HIV test, and the lab report number as assigned by the lab to the local health department.<sup>90</sup> After receiving the results from the lab, the health care provider transfers the completed HIV/AIDS Confidential Case Report form, including the UI (partial code plus last four digits of the patient’s social security number), name, address, and phone number of provider, and race/ethnicity addendum to the local health department.<sup>91</sup> Next, the local health department submits the information to the state Department of Health Services, Office of AIDS (DHS), using the UI created by the health care provider.<sup>92</sup> Finally, DHS submits the aggregate HIV case data to the CDC, absent the UI code.<sup>93</sup> Perhaps, by this description of the process, one can sympathize with the Commission’s recommendation to replace the UI method with one that merely requires the recitation of a first and last name.<sup>94</sup>

### C. Anonymous HIV Testing

Whether or not a state uses name-based or unique identifier HIV reporting, individuals may be tested at an anonymous test site or by anonymous physician test. Only results from confidential testing are reportable, therefore anonymous testing remains an option for individuals who truly fear having their HIV diagnosis reported by name or even having their name associated with a unique identifier

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88. HIV Non-Name Code Reporting, *supra* note 85, at 1.

89. *Id.*

90. *Id.*

91. *Id.*

92. *Id.*

93. *Id.*

94. However, the Commission acknowledges that most laboratories are complying with the current system and completeness of data on individual case reports is comparable to that of AIDS case data. HIV Reporting in L.A. County, *supra* note 30. See *infra* Part V for further discussion of the strengths and weaknesses of each system.



code.<sup>95</sup> At an anonymous test site, general demographic information is recorded, such as race, ethnicity, sex, age, and gender.<sup>96</sup> Names, addresses, birth dates, or social security numbers are not disclosed.<sup>97</sup> If the person tests positive for HIV, the combined information is transferred to public health officials, void of personal identification.<sup>98</sup> The disadvantage to anonymous testing is that an individual will only be able to receive their result verbally. The testing site will not provide any tangible proof the person was tested or that the result was negative or positive. This can potentially hinder the person. For example, some agencies, such as HIV/AIDS Legal Services Alliance (HALSA), require evidence of HIV-positive status to obtain free legal services.<sup>99</sup> In other cases, a partner may want confirmation their mate has been tested and of the result before proceeding with the relationship.

## VI. CONSTITUTIONAL ISSUES

### *A. Right to Privacy*

#### 1. Jacobson v. Massachusetts

The Supreme Court has not addressed the right of privacy as relating to mandatory HIV reporting schemes. However, the Court has addressed the scope of the state's police power to protect public health and safety and held a statute requiring smallpox vaccination of adults did not violate the Fourteenth Amendment of the

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95. Cal. Dep't of Health Servs., A Brief Guide to California's HIV/AIDS Laws 4-5 (Mar. 2004) (last visited on February 2, 2005) [hereinafter A Brief Guide to HIV/AIDS Laws]. See also The Body: The Complete HIV/AIDS Resource, <http://www.thebody.com/cdc/testing/testing.html> (last visited on Oct. 28, 2004), for general information about anonymous HIV testing and site locations.

96. A Brief Guide to HIV/AIDS Laws, *supra* note 95.

97. *Id.*

98. In support of its intent to replace the current unique identifier system with names-based reporting, the Los Angeles Commission on HIV Health Services "strongly supports the continued availability of anonymous testing and would oppose any change." Commission Paper on HIV Health Services, *supra* note 5, at 1.

99. See <http://www.halsaservices.org> (last visited on Sept. 26, 2004).

Constitution.<sup>100</sup> In *Jacobson v. Massachusetts*, plaintiff argued that a statute's smallpox vaccination requirement violated the Fourteenth Amendment and "tended to subvert and defeat the purposes of the Constitution as declared in its Preamble."<sup>101</sup> The Court recognized the state's authority to enact various regulations "to safeguard the public health and the public safety."<sup>102</sup> Further, the Court noted the state's power to restrict an individual's liberty to secure the general comfort, health, and wellbeing of its citizens.<sup>103</sup> Weighing state police power to protect the people against the rights of the individual, the Court determined that protecting the public against a potential smallpox epidemic outweighed the individual's right to refuse the vaccination because the vaccination was a reasonable means to prevent the spread of such disease.<sup>104</sup> Therefore, the Court upheld the statute as constitutional.<sup>105</sup>

## 2. *Griswold v. Connecticut*

The Constitution does not explicitly establish an individual right to privacy, however this does not mean one does not exist. The Court in *Griswold* established such a right by way of the Bill of Rights.<sup>106</sup> This landmark case interpreted the First, Third, Fourth, Fifth, and Ninth Amendments to denote a privacy right to all citizens.<sup>107</sup> In 1965, Planned Parenthood League's executive director and medical director, convicted as accessories for providing information, instruction, and medical advice to married couples as to methods of preventing conception, alleged the Connecticut law forbidding use of contraceptives violated the Fourteenth Amendment.<sup>108</sup> The Court ruled that, although not a "super-legislature" meant to interpret the

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100. *Jacobson v. Massachusetts*, 197 U.S. 11, 12, 39 (1905).

101. *Id.* at 13-14.

102. *Id.* at 25. The Court also recognized the state's authority to quarantine a citizen "against his will." *Id.* at 29.

103. *Id.* at 26.

104. *Id.* at 39.

105. *Id.*

106. *Griswold v. Connecticut*, 381 U.S. 479, 482 (1965).

107. *Id.* at 484.

108. *Id.* at 480.

reasoning behind a statute,<sup>109</sup> the Court was charged with protecting certain fundamental rights, even if those rights were not explicit in the Constitution.<sup>110</sup> The Court then noted the association of people is not mentioned in Constitution, or the Bill of Rights, but has been “construed” as inviolable nonetheless.<sup>111</sup> Finally, the Court balanced the individual’s privacy interest against the state’s police power to invade the marital bedroom, and held the law was unjustified because it was an overly broad governmental intrusion into an area of protected freedoms.<sup>112</sup> In sum, the Court held the Connecticut statute prohibiting the use of contraception by married couples violated the constitutional right to privacy.<sup>113</sup>

Clearly, there is a privacy right within one’s marriage. However, the question remains how far this right extends.

### 3. *Whalen v. Roe*

In *Whalen v. Roe*, the Court addressed the issue of whether New York, in an attempt to prevent an illegal drug market, could require a record of names and addresses of all persons taking certain medications.<sup>114</sup> In *Whalen*, patients and physicians brought suit to enjoin enforcement of a statute that required physicians to produce copies of prescriptions of certain drugs to the State Health Department for entry into the State’s computerized database.<sup>115</sup> The district court held the statute intruded upon the “doctor-patient” relationship with a “needlessly broad sweep.”<sup>116</sup> The Supreme Court

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109. *Id.*

110. *Id.*

111. *Id.* The Court also lists the right to educate a child in a school of the parent’s choice, the right to study a foreign language, the right to distribute, receive, and read, and the freedoms of inquiry, thought, to teach, and of the entire university community. *Id.* None of the foregoing are explicit, but the “Bill of Rights have penumbras, formed by emanations from those guarantees that help give them life and substance.” *Id.* at 484.

112. *Id.* at 485.

113. *Id.* at 486.

114. *Whalen v. Roe*, 429 U.S. 589, 590 (1977).

115. *Id.* at 589.

116. *Id.* at 595. The district court noted: “the doctor-patient relationship is one of the zones of privacy accorded constitutional protection.” *Id.*

disagreed, holding the statute was a reasonable exercise of the State's broad police power by recognizing New York's "vital interest in controlling the distribution of dangerous drugs."<sup>117</sup> Further, there was no cause to assume the security safeguards of the statute would be improperly administered.<sup>118</sup> The Court then recognized two different applications of the constitutional right to privacy: "the individual interest in avoiding disclosure of personal matters, and the interest in making certain kinds of important decisions."<sup>119</sup>

Acknowledging that some people may defer much needed medical treatment due to concerns of stigma or privacy, the Court reasoned disclosure of information to medical personnel does not "automatically amount to an impermissible invasion of privacy" because such an exchange is often part of regular medical encounters.<sup>120</sup> The Court noted, for example, that statutory reporting requirements for venereal disease, child abuse, injuries caused by deadly weapons and certifications of fetal death could likewise be justified as essential to modern medical practice, despite similar potential for poor reflection on the character of the individual.<sup>121</sup> In addition, the Court pointed out the New York statute did not deprive the patient of access to medication because it did not prohibit use entirely, nor condition access on the consent of "any state official or other third party."<sup>122</sup> Again, balancing these concerns against the State's interest, the Court held the statute did not impermissibly violate the patient's privacy rights.<sup>123</sup>

The Court included a "final word" about matters left unaddressed.<sup>124</sup> Noting the "threat to privacy implicit in the

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117. *Id.* at 598.

118. *Id.* at 601. The statute does not "pose a sufficiently grievous threat to either interest to establish a constitutional violation," at least on its face. *Id.* However, the Court does acknowledge that some people's concern may deter them from seeking "needed medical attention." *Id.* Regardless, disclosure of medical information is "often an essential part of modern medical practice even when the disclosure may reflect unfavorably on the character of the patient." *Id.* at 602.

119. *Id.* at 599-600.

120. *Id.* at 590.

121. *Id.*

122. *Id.* at 603.

123. *Id.* at 604.

124. *Id.* at 605.

accumulation of vast amounts of personal information,” the Court recognized the governmental duty to avoid disclosure, rooted in the Constitution.<sup>125</sup> The Court then stated it had not decided any issue regarding the unauthorized disclosure of private data, whether intentional or unintentional or under a statute with insufficient safeguards.<sup>126</sup> However, as to the case at hand, the Court held that the New York statute did not violate the patient’s constitutional right to privacy.<sup>127</sup>

There are two points in *Whalen* that resonate for mandatory HIV reporting. First, the mere possibility of a breach of medical information is not facially unconstitutional. And second, the Court acknowledged some New York citizens may avoid or postpone treatment because of stigma or other privacy concerns. Disclosure, the Court found, is part of modern medicine and “does not automatically amount to an impermissible invasion of privacy.”<sup>128</sup> Therefore, a claim cannot rest solely on a future breach argument.

#### 4. United States v. Westinghouse

In *United States v. Westinghouse*, the United States Court of Appeals for the Third Circuit held that the National Institute for Occupational Safety and Health’s (NIOSH) access to the medical records of certain employees did not violate their constitutional right to privacy.<sup>129</sup> After a request for a health hazard evaluation from a Westinghouse employee, NIOSH sought access to medical records of Westinghouse employees who may have been exposed to dangerous chemicals in the plant.<sup>130</sup> The district court relied on *Whalen*, holding public interest granted NIOSH the authority to view the medical records.<sup>131</sup> The court of appeals affirmed, but used strong language regarding a citizen’s constitutional right to privacy.

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125. *Id.*

126. *Id.*

127. *Id.* at 603-04.

128. *Id.*

129. *United States v. Westinghouse Elec. Corp.*, 638 F.2d 570, 580 (3d Cir. 1980).

130. *Id.* at 570, 572.

131. *Id.* at 573.

Recognizing the sensitive nature of information concerning one's body and health status, the court reasoned "an employee's medical records, which may contain intimate facts" clearly fall within a zone entitled to privacy protection.<sup>132</sup> However, the court noted that intrusion into this zone is justified if the societal interest in disclosure outweighs the privacy interest in the specific facts at hand.<sup>133</sup> The court identified seven factors to be weighed in deciding whether disclosure of personal information is justified: (1) the type of record requested, (2) the information it does or might contain, (3) the potential for harm by subsequent nonconsensual disclosure, (4) the 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 toward access.<sup>134</sup>

Balancing these factors, the court concluded the strong public interest in occupational safety and health, the fact that the records were reasonably related to the inquiry, and adequate safeguards against unauthorized disclosure justified the intrusion into the employee's medical records.<sup>135</sup> Thus, the court concluded NIOSH's access to certain employee's medical records did not violate their constitutional right to privacy.<sup>136</sup>

The seven *Westinghouse* factors may be particularly useful in determining whether HIV reporting, specifically mandatory, name-based reporting systems, is justified or whether an individual's right to privacy remains constitutionally protected. The following line of cases directly addresses the issue of whether an individual has a constitutional right to privacy in their HIV/AIDS status.

##### 5. Doe v. Borough of Barrington

The United States District Court for the District of New Jersey held in *Doe v. Borough of Barrington* that a police officer's disclosure

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132. *Id.* at 577.

133. *Id.* at 578.

134. *Id.*

135. *Id.* at 578-80.

136. *Id.* at 580.

of an individual's AIDS status violated the individual's and the family's right to privacy under the Fourteenth Amendment.<sup>137</sup> In *Borough of Barrington*, plaintiffs alleged they suffered harassment, discrimination, and humiliation after an officer disclosed to neighbors that "Doe" had AIDS.<sup>138</sup> The court held the right to privacy in this case "extends to members of the AIDS patient's immediate family" because of the broad impact of the disclosure of such sensitive medical information.<sup>139</sup> The court then reasoned the privacy interest in one's AIDS status is greater than in other medical records because of the stigma that accompanies the disease.<sup>140</sup> In holding that an individual's privacy interest in medical information and records is not absolute, the court stated the government must demonstrate a compelling interest in invading that privacy.<sup>141</sup> The court found that disclosure of Doe's confidential information did not advance a compelling government interest in preventing the spread of the disease because there was no risk that the neighbors might be exposed to the virus through casual contact with Doe or his family.<sup>142</sup> In conclusion, the court held the police officer's disclosure regarding an individual's AIDS status violated the constitutional right to privacy.<sup>143</sup>

## 6. Doe v. City of New York

In *Doe v. City of New York*, the United States Court of Appeals for the Second Circuit held that there is a constitutional right to privacy in

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137. *Doe v. Borough of Barrington*, 729 F. Supp. 376, 385 (D. N.J. 1990).

138. *Id.* at 579.

139. *Id.* at 584. "The stigma attaches not only to the AIDS victim, but to those in contact with AIDS patients." *Id.* "Revealing that one's family or household member has AIDS causes the whole family to be ostracized." *Id.* at 585.

140. *Id.* at 584. Further, the court acknowledges the greater social impact on the individual. For example, "moral judgments about the high-risk activities associated with the disease, including sexual relations and drug use" heighten the need to protect one's right to privacy in their AIDS condition. *Id.* at 583. "The potential for harm in the event of nonconsensual disclosure is substantial; plaintiff's brief details the stigma and harassment that comes with public knowledge of one's affliction with AIDS." *Id.*

141. *Id.* at 585.

142. *Id.*

143. *Id.*

one's HIV status.<sup>144</sup> In *City of New York*, plaintiff alleged his right to privacy was violated when the City of New York publicly revealed details of a discrimination suit settlement against Delta Airlines based on Doe's HIV status.<sup>145</sup> The district court granted the City's motion to dismiss, finding the matter of public record once the original discrimination complaint was filed.<sup>146</sup> The Second Circuit found for the plaintiff, reasoning the right to privacy includes an individual's right to avoid disclosure of one's health status because of its personal nature.<sup>147</sup> Further, the court held this is especially relevant for individuals infected with HIV and AIDS because revealing their positive status may subject them to discrimination or intolerance.<sup>148</sup> In sum, there is a constitutional right to privacy in one's HIV status. This ruling is of great importance to those people infected with the disease, as well as to evaluations of HIV surveillance.

## 7. Doe v. Wigginton

The Sixth Circuit held in *Doe v. Wigginton* that the disclosure to a corrections officer of a prisoner's HIV status did not violate the prisoner's constitutional right to privacy.<sup>149</sup> In *Wigginton*, a prisoner claimed his constitutional right to privacy was violated when a prison officer opened a "confidential" medical file containing information regarding the prisoner's HIV-positive condition.<sup>150</sup> The court reiterated "a constitutional right of nondisclosure would force courts

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144. *Doe v. City of New York*, 15 F.3d 264, 267 (2d Cir. 1994).

145. *Id.* at 265.

146. *Id.* at 266.

147. *Id.* at 267. The court further distinguished the right to privacy as a right to "confidentiality" and held "the right to confidentiality includes the right to protection regarding information about the state of one's health." *Id.*

148. *Id.* Admitting this is an unfortunate truth "among many in this society" about people infected with "a fatal, incurable disease." *Id.* This case was written more than a decade ago. Though HIV and AIDS are no longer necessarily fatal, they remain incurable. Further, the stigma, discrimination, and intolerance that attaches to HIV and AIDS continues to be the prevailing social sentiment. This not only causes people to keep their status confidential, it may result in their avoidance of the issue altogether – including not getting tested for the disease at all. See discussion *infra* Parts V.a.3, 4.

149. *Doe v. Wigginton*, 21 F.3d 733, 740 (6th Cir. 1994).

150. *Id.* at 736.



to ‘balance almost every act of government, both state and federal, against its intrusion on a concept so vague, undefinable, and all-encompassing as individual privacy.’”<sup>151</sup> The court then noted that inferring broad constitutional rights not expressly granted by the Constitution is not a proper role for the judiciary.<sup>152</sup> Therefore, because the Constitution “does not encompass a general right to nondisclosure of private information,” the court held there was no violation of the prisoner’s constitutional rights.<sup>153</sup>

#### 8. Doe v. Marsh

In *Doe v. Marsh*, the United States District Court for the Northern District of New York held the constitutional right to privacy in one’s HIV or AIDS status is conditional and may be overcome by (1) the government’s interest in having or using the information or (2) a waiver of the right through an individual’s prior disclosure.<sup>154</sup> In *Marsh*, the New York State Education Department published an HIV awareness guidance document.<sup>155</sup> The document contained the full names of individuals living with HIV, including those of the two plaintiffs.<sup>156</sup> The plaintiffs claimed that while participating in the program to create the document, neither had disclosed their full name and none of the discussions were open to the public, though they were both otherwise active in the HIV/AIDS advocacy community.<sup>157</sup> Therefore, plaintiffs argued they had not waived their right to privacy in their HIV status.<sup>158</sup> The defendants countered that regardless of whether plaintiffs had waived their right to privacy, they were entitled to qualified immunity because the right to privacy was not “well-settled” at the time the events took place.<sup>159</sup>

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151. *Id.* at 740 (quoting *J.P. v. DeSanti*, 653 F.2d 1080 (6th Cir. 1981)).

152. *Id.*

153. *Id.*

154. *Doe v. Marsh*, 918 F. Supp. 580, 585-86 (N.D.N.Y. 1996).

155. *Id.* at 583. The document was intended for those who wished to create programs to help prevent the spread of HIV and that employed the services of people who were infected with HIV or AIDS. *Id.*

156. *Id.*

157. *Id.*

158. *Id.*

159. *Id.*

Evaluating the totality of the circumstances, the court held that when the events occurred in 1992, it was clear the right to privacy was not absolute.<sup>160</sup> The court then stated what was unclear was what constitutes a waiver under New York law but concluded the plaintiffs' actions would allow a reasonable person to find they had waived their rights.<sup>161</sup>

### *B. Equal Protection*

The Equal Protection Clause of the Fourteenth Amendment requires states to treat similarly situated people in a similar way.<sup>162</sup> The Clause does not prohibit states from classifying its citizens, so long as such classifications are not made arbitrarily.<sup>163</sup> The Supreme Court has established three standards of review for equal protection claims: strict scrutiny, where a government action must be based on a compelling government interest; intermediate scrutiny, when an action must be substantially related to an "important" government interest; and a rational basis test, where an action must be "rationally related" to a legitimate government interest.<sup>164</sup> The nature of the allegedly discriminatory classification determines the standard used, however, laws regarding individuals with HIV or AIDS would most likely be evaluated under the rational basis test, asking whether the law is rationally related to a legitimate governmental interest.

#### 1. *Romer v. Evans*

In 1996, the Supreme Court ruled that a Colorado constitutional amendment prohibiting individuals who are "homosexual, lesbian, or bisexual" any legislative, judicial, or civil rights protections, violated the Equal Protection Clause.<sup>165</sup> In *Romer v. Evans*, plaintiffs sought to enjoin enforcement of Amendment Two of the Colorado

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160. *Id.* at 585 (citing *Whalen v. Roe*, 429 U.S. 589, 599 (1977) and *Doe v. City of New York*, 15 F.3d 264, 269 (2d Cir. 1994)).

161. *Id.* at 586-87.

162. *See* *Lindsley v. Natural Carbonic Gas Co.*, 220 U.S. 61, 83 (1911).

163. *Id.* at 78, 83.

164. *See generally* PROCESS OF CONSTITUTIONAL DECISIONMAKING CASES AND MATERIALS (Paul Brest et al. eds., 4th ed. 2000).

165. *Romer v. Evans*, 517 U.S. 620, 624 (1996).

Constitution, claiming it violated the Equal Protection Clause of the Fourteenth Amendment.<sup>166</sup> The Court stated that where a law neither impairs a fundamental right, nor implicates a suspect class, a state statute will be upheld if rationally related to a legitimate state interest.<sup>167</sup> The Court then evaluated the State's claim that it was protecting its citizens' First Amendment rights,<sup>168</sup> determining the Colorado amendment imposed discriminatory practices upon a single group of people, inflicting upon gay, lesbian, and bisexual people "immediate, continuing and real injuries that outrun and belie any legitimate justifications that may be claimed for [the amendment]."<sup>169</sup> Because the Constitution does not permit disadvantage "born of animosity," the Court held Amendment Two violated the Equal Protection Clause.<sup>170</sup>

Regarding HIV surveillance programs, this case would probably be of little help. The Colorado amendment expressly stated homosexuals and bisexuals in its language, classifying a separate and identifiable group. Most name-based reporting systems would not distinguish HIV-positive homosexuals from HIV-positive heterosexuals or any other group. If this was the case, the statute would most likely not pass the rational basis test. Further, this would not promote the ultimate goal of stopping the spread of HIV in the general population. The case above would be helpful, however, in an action against the denial of homosexual or bisexual rights specifically.

## 2. *Middlebrooks v. State Board of Health*

In *Middlebrooks v. State Board of Health*, the Supreme Court of Alabama held that the State's statute requiring name-based reporting for certain diseases and conditions, including HIV and AIDS, did not violate the individual's right to privacy or the physician's right to equal protection.<sup>171</sup> In *Middlebrooks*, the state health department

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166. *Id.* at 624-25.

167. *Id.* at 631.

168. *Id.* at 635. The State argued its concern was "for other citizens' freedom of association, and in particular the liberties of landlords or employers who have personal or religious objections to homosexuality." *Id.*

169. *Id.*

170. *Id.* at 634-35.

171. *Middlebrooks v. State Bd. of Health*, 710 So. 2d 891, 893 (Ala. 1998).

brought suit against a physician for failing to report the names and addresses of his HIV-positive patients, as required by statute.<sup>172</sup> The physician made two arguments. First, he claimed the name-based reporting requirement violated his patients' right to privacy in their HIV status and, second, the statute violated the Equal Protection Clause because manufacturers of confidential HIV-testing kits are similarly situated to him, but are not required to report the names and addresses of the purchasers.<sup>173</sup> Addressing the right to privacy in medical information relating to diseases such as HIV and AIDS, the court weighed the *Westinghouse* factors and held that preventing the spread of the virus is a legitimate governmental interest.<sup>174</sup> Further, there are adequate safeguards to prevent unauthorized disclosure of the medical records.<sup>175</sup> In addition, the court reasoned the State can require disclosure to state representatives responsible for the health of the community; thus, the statute's disclosure requirement in this case did not impermissibly violate an individual's privacy right.<sup>176</sup> Regarding the physician's equal protection claim, the court determined that the state's classification was reasonable because the manufacturers of confidential HIV-testing kits are out-of-state and do not know the identities of the persons being tested.<sup>177</sup> Further, they have no information about the purchaser's HIV status, in contrast to physicians who do gather this information.<sup>178</sup> Therefore, the court upheld the state's name-based reporting statute because there was neither a violation of HIV-positive individuals' constitutional right to privacy, nor the physician's rights under the Equal Protection Clause.<sup>179</sup>

The effect of this ruling would appear as follows. As long as the state or federal regulation provides adequate safeguards ensuing non-disclosure, a court applying the *Westinghouse* factors will most likely rule in favor of its validity. Further, the seventh factor, "whether

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172. *Id.* at 892.

173. *Id.*

174. *Id.* at 893.

175. *Id.*

176. *Id.*

177. *Id.*

178. *Id.*

179. *Id.*

there is an express statutory mandate, articulated public policy, or other recognizable public interest militating toward access," seems to be broad enough to incorporate a name-based reporting system.<sup>180</sup>

An argument under the Equal Protection Clause may have greater strength. In *Middlebrooks*, the court did not address whether an in-state manufacturer or vendor is "similarly situated" to an in-state doctor.<sup>181</sup> This line of reasoning may prove convincing.

## V. IMPACT

### A. Concerns

HIV was identified in 1983 and the test for HIV antibodies became available a few years later.<sup>182</sup> Since that time, there has been considerable dissention about whether the names of those infected with HIV, in addition to the mere fact of infection, should be reported to state and federal public health agencies. This part discusses several of the issues that surround the ongoing debate.

#### 1. Funding

One of the most influential factors in support of HIV reporting is that federal funding is often allocated based on the impact of the epidemic on states, which depends on HIV data as well as AIDS cases.<sup>183</sup> Because of this, some commentators believe that those states that report HIV cases by code, such as California, will not be able to adequately express their true need for federal assistance.<sup>184</sup> States such as California will therefore be at a disadvantage and theoretically shoulder more than their share of the burden.<sup>185</sup>

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180. *United States v. Westinghouse Elec. Corp.*, 638 F.2d 570, 580 (3d Cir. 1980)

181. *Middlebrooks*, 710 So. 2d at 893.

182. *See AEGIS*, *supra* note 24.

183. *See California Performance Review*, *supra* note 7.

184. *Id.*

185. *Id.*

Laws concerning HIV testing and surveillance were affected by the reauthorization of the Ryan White CARE Act in 2000.<sup>186</sup> Prior, funding for this and other federal AIDS programs were based on AIDS surveillance data.<sup>187</sup> With increasing awareness of the limitations of this information,<sup>188</sup> the new law requires that HIV case data be incorporated into the total count for local and state areas beginning in 2005, unless it is determined at that time that adequate data is not yet available.<sup>189</sup>

In addition, the retooled CARE Act creates incentives for states to employ name-based HIV reporting systems.<sup>190</sup> The Act now establishes a thirty million dollar authorization to increase partner notification programs.<sup>191</sup> In order to receive these funds, states must

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186. Dept. of Health and Human Services, Fact Sheet: Ryan White Comprehensive AIDS Resources Emergency (CARE) Act (Dec. 18, 1998), available at <http://www.hhs.gov/news/press/1998pres/981218d.html> (last visited on February 2, 2005) [hereinafter White Fact Sheet]. The Ryan White CARE Act was passed by an overwhelming bipartisan majority on August 18, 1990, in honor of Ryan White, a teenager from Indiana whose experience with AIDS helped educate the nation about the range of needs of people with the disease. *Id.* The Act supports the development of systems of HIV/AIDS care at the local level and seeks to establish less expensive outpatient and primary care and prevent costly emergency room and hospital visits. *Id.* Sadly, Ryan died on April 8, 1990, just a few months before Congress passed the Act in his name. *Id.*

187. *Id.*

188. See discussion *supra* Part III.

189. Chris Collins, HIV/AIDS Surveillance and Reporting in the United States (Feb. 2001) at <http://hivinsite.ucsf.edu> (last visited Sept. 24, 2004).

190. See White Fact Sheet, *supra* note 186.

191. Collins, *supra* note 189. Partner notification or “contact tracing” is another means by which public health officials identify and contact people who may have been exposed to a particular disease. *Id.* Partner notification for HIV has long been a controversial subject, as many find it an invasion of privacy and may discourage people from seeking HIV testing and treatment from government agencies. *Id.* Under the 2000 CARE Act, programs receiving Title III funds must inform individuals during post-test counseling that “it is the duty of infected individuals to disclose their status” to partners. *Id.* While the San Francisco AIDS Foundation concedes partner notification is an important component to halting the spread of the disease, the process can only take place if people get tested in the first place. San Francisco AIDS Foundation: HIV Reporting and Partner Notification in California at [http://www.sfaf.org/policy/partner\\_notification.html](http://www.sfaf.org/policy/partner_notification.html) (last visited on Sept. 26, 2004). The Foundation expressed concern that name-based reporting deters some individuals from getting tested, thus they never learn their HIV status and, in turn, are unable to inform their partners of the potential risk. *Id.* The

implement partner notification programs, as well as conduct HIV reporting in a manner recommended by the CDC.<sup>192</sup> The law further states preference will be given to “states that have HIV reporting systems that are ‘sufficiently accurate and reliable.’”<sup>193</sup> The new CARE Act raises the concern that incentives for name-based reporting will lead more states to use this method.<sup>194</sup>

## 2. Treatment

As this comment acknowledges, fewer people are dying of AIDS and the number of AIDS cases each year is declining, due in large part to modern treatment and drug therapies.<sup>195</sup> These trends are expected to continue as more individuals infected with HIV are

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Foundation urges California to maintain the unique identifier HIV reporting system to “ensure confidentiality and enhance the trust of individuals testing for HIV,” ultimately resulting in more effective partner notification. *Id.* Also in support of this argument, the Lambda Legal Defense and Education Fund notes data indicates “people who refuse to participate in partner notification do so because of fear that their anonymity will be compromised or that their partners might retaliate against them.” Hanssens, *supra* note 70.

192. The CDC considers HIV data from code-based systems to be unreliable and will not include the data in nationally accumulated HIV infection case count totals until it has passed a quality review by the Institute of Medicine. National Center for HIV, STD and TB Prevention: Centers for Disease Control, 14 HIV/AIDS SURVEILLANCE REPORT, Technical Notes 33, *available at* <http://www.cdc.gov/hiv/stats/hasr1402/technotes.htm> (last visited Sept. 16, 2005). The Commission argues the CDC is unlikely to confirm California’s current information for use in allocating Ryan White funds and could cost the state up to fifty million dollars and cause reduced services to clients. California Performance Review Report, *supra* note 183.

193. White Fact Sheet, *supra* note 186.

194. In response to the revamped 2000 CARE Act, California Senator Dianne Feinstein noted the CDC “has the technical capacity to accept code-based data” and, along with Massachusetts Senator Edward Kennedy and thirteen other members of Congress, requested the CDC take immediate steps to accept HIV data from all states, including those that do not report by name. Press Release, Office of Senator Dianne Feinstein, Senator Feinstein Calls on CDC to Accept California’s HIV Data (May 4, 2004), *available at* <http://feinstein.senate.gov/04Releases/r-cdc-hiv.htm> (last visited Sept. 26, 2004). Apparently, the Commission will not find support for its cause in this Sacramento office.

195. *See* discussion *supra* Part III.

treated.<sup>196</sup> However, early detection and treatment are crucial.<sup>197</sup> New combination drug therapies with protease inhibitors have improved the health and prolonged the life of people infected with HIV.<sup>198</sup> Studies suggest the treatment not only helps the patient but also decreases the likelihood of transmission.<sup>199</sup> Studies also show that such therapies are more effective the earlier they are initiated in the course of the HIV disease.<sup>200</sup> Thus, more so than when there were fewer effective treatment options and less need for early detection, there may be a compelling argument for an HIV reporting system that provides links between patient and treatment, namely name-based reporting. On the other hand, if concern over having one's name reported deters some people from getting tested "some individuals will not learn their HIV status at all"<sup>201</sup> and some studies have found "no connection between name reporting and health department follow-up" or improved access to health care services.<sup>202</sup>

Early testing is critical not only for treatment purposes, but to stop individuals from unwittingly passing the virus to others.<sup>203</sup> In either case, it is clear the present impact of the epidemic will be increasingly difficult to evaluate without *some* sort of HIV reporting data.

### 3. Stigma and Deterrence

The notion that AIDS is a highly infectious disease contributes to the stigmatization of those who are infected. In fact, HIV, the virus

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196. *See id.*

197. *See* AEGIS, *supra* note 24.

198. *See id.*

199. *See id.*

200. *See id.*

201. Collins, *supra* note 189.

202. San Francisco AIDS Foundation, HIV Reporting and Partner Notification in California, *supra* note 191. In addition, the Foundation found people testing positive for HIV in states that use code systems receive referrals upon learning of their status. *Id.* Further, in these states "because people tend to test closer to their date of initial infection," they actually receive care sooner than in a name-based reporting system. *Id.* The Lambda Legal Defense Fund also argues "people with HIV do not get into care after testing positive at sites where names are reportable any faster than after being tested at anonymous sites [where names are not used]." Hanssens, *supra* note 70.

203. Ornstein, *supra* note 52, at 3.



that causes AIDS, is not spread by casual contact.<sup>204</sup> HIV is not transmitted through the air or through skin-to-skin contact or other informal touching.<sup>205</sup> Rather, the virus is generally transmitted through the exchange of blood, semen, vaginal secretions, or from mother to child during childbirth or through breastfeeding.<sup>206</sup> Thus, in truth it is not easily spread.<sup>207</sup>

The social stigma that may accompany public knowledge of a person's HIV status may discourage individuals from getting tested or seeking treatment.<sup>208</sup> One study found that of those who delayed accessing care more than one month after testing positive, ten percent cited fear of being reported to the government as a reason.<sup>209</sup> The UI system preserves anonymity, names are not collected into a single registry and there are fewer confidentiality concerns. Those who fear stigmatization and discrimination, and those who do not but would still prefer to remain un-named, will be encouraged to get tested and the public health need for HIV data collection will be fulfilled.

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204. See AEGIS, *supra* note 24.

205. See *id.*

206. See *id.*

207. Though this is true for the disease, some advocates argue HIV should be included on California's list of eighty required name reported diseases, along with AIDS, syphilis, food poisoning, and measles. Ornstein, *supra* note 52, at A1. The article quotes the president of the Los Angeles AIDS Healthcare Foundation, claiming that as long as HIV is treated as "special and separate and so dreaded that you can't even talk about it, then it's going to reinforce that view." *Id.*

208. "It's not so much, 'Will the state know?' as much as, 'Who else is going to? . . . People are so paranoid about other people finding out.'" *Id.* at A3. For Latino and other immigrant communities, a name-based reporting system would have "particularly negative public health consequences." Martha Escutia, *AIDS Is Still Stigmatized*, L.A. TIMES, Jan. 17, 2000, at A5. The Latino community has a general distrust of the government. Coupled with the fear that one's HIV status could affect immigration status, HIV name reporting would likely be a strong deterrent for this community in getting tested. *Id.*

209. San Francisco AIDS Foundation, *HIV Reporting and Access to Care Services in California* at [http://www.sfaf.org/policy/access\\_care.html](http://www.sfaf.org/policy/access_care.html) (last visited on Sept. 26, 2004). A 1999 study found that sixty-three percent of forty-two repeat testers would forego testing if name reporting was required. HIV Reporting in L.A. County, *supra* note 30, at A3. However, this study had few participants and did not mention the availability of anonymous testing. *Id.*

Another study reported only a small proportion of respondents even knew which HIV reporting system was used by their state.<sup>210</sup> The main factors cited for not being tested or delaying testing were: fear of learning they were HIV positive, thinking they were unlikely to have been exposed, thinking they were negative, not wanting to think about being positive, and thinking there was little they could do if they were HIV positive.<sup>211</sup> Of those participants who have never been tested, concern about having one's name reported to the government was cited as one of the factors for not testing for nineteen percent of the respondents and the "main factor" for two percent.<sup>212</sup> Regardless, due to the different, but equally significant impact of either name-based or UI HIV reporting in deciding which surveillance system to use, a state should give proper consideration to all of the factors involved in the decision to get tested.

Any surveillance system must acknowledge and account for social stigma and potential deterrent effects by ensuring the protection of the privacy interests of HIV infected individuals. There should be punishment for intentional or negligent disclosure. Otherwise, the social risks may outweigh the public health benefits, tilting the balance toward having no surveillance system at all. Finally, to ensure the HIV reporting system does not deter even a small number of people from seeking testing, the CDC recommends that all states continue to make anonymous testing available.<sup>213</sup>

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210. CDC, *HIV Testing Among Populations at Risk for HIV Infection*, 47 MORTALITY & MORBIDITY WKLY REP. 108 (1998), available at <http://www.thebody.com/cdc/testing/testing.html> (last visited on Oct. 28, 2004).

211. *Id.*

212. *Id.* Another study by the San Francisco Department of Public Health supported this conclusion, finding "fear of reporting is an infrequently cited reason for deterring or delaying testing." S. Schwarcz et al., *Does Name-based HIV Reporting Deter High-Risk Persons from HIV Testing? Results from San Francisco*, 35(1) J. ACQUIRED IMMUNE DEFICIENCY SYNDROME 93 (2004). However, doctors at the University of California at San Francisco (UCSF) concluded name-based HIV reporting systems "could be related to delays in testing." *Name-based HIV Reporting Policies Do Not Deter Testing*, CDC HIV/STD/TB PREVENTION NEWS, Oct. 16, 2000, <http://www.aegis.com/news/ads/2000/AD001876.html> (last visited on Sept. 26, 2004).

213. Ornstein, *supra* note 52, at A4.

#### 4. Confidentiality Concerns

Public health authorities have the duty to act in order to protect the public health. One of the most useful and frequently used methods of protecting the public involves surveillance systems to track infectious diseases.<sup>214</sup> Such systems work by connecting infected individuals to resources for treatment and support services.<sup>215</sup> Surveillance systems also help officials understand the impact of a disease, monitor its progression, guide allocation of resources, and evaluate the effectiveness of interventions.<sup>216</sup> However, federal tracking systems have always raised concerns about civil liberties and interference with the doctor-patient relationship.<sup>217</sup>

HIV is an infectious disease and public health officials maintain it should be reported in the same manner as other such conditions, such as hepatitis, measles, and AIDS.<sup>218</sup> Supporters of the name-based system note states already have the names of HIV patients on file if they receive care under federally funded programs, such as

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214. HIV Reporting in L.A. County, *supra* note 30. For a complete list of California's reportable diseases and conditions, *see* <http://lapublichealth.org/acd/reports/diseasepluscmr.pdf> (last visited on Sept. 26, 2004).

215. HIV Reporting in L.A. County, *supra* note 30.

216. *See id.* at 2.

217. *See generally* MARK S. SENAK, HIV, AIDS, AND THE LAW: A GUIDE TO OUR RIGHTS AND CHALLENGES (1996). Though there have been few recent breaches of security in states that use name-based surveillance, opponents of the system point to the following incident of information misuse. In Florida, a county health worker brought home lists of HIV and AIDS patients' names to determine the medical status of potential sexual partners. Craig Pittman, *Mortician Guilty of Revealing AIDS List*, ST. PETERSBURG TIMES, Apr. 30, 1997, at 1B. A friend copied the list and mailed the names of over 4,000 Florida residents to local newspapers. *Id.* Also, in Illinois, a statute was enacted authorizing the state to go through its registry of HIV infected persons in order to determine the HIV status of state health care workers. ACLU, *HIV Surveillance and Name Reporting: A Public Health Case for Protecting Civil Liberties* (Oct. 1997), available at <http://www.aclu.org/Privacy/Privacy.cfm?ID=14512&c=27> (last visited on Oct. 17, 2005). The statute also authorized the state to notify former patients of their potential exposure to the virus. *Id.*

218. Ornstein, *supra* note 52. "As long as we treat it [HIV] as something special and separate and so dreaded that you can't even talk about it, then it's going to reinforce that view." *Id.*

Medicaid.<sup>219</sup> Furthermore, HIV reporting will result in earlier treatment, improved tracking of infected persons, and increase the testing of partners.<sup>220</sup>

Those who prefer using codes argue the government will misuse this sensitive data to deny medical insurance and employment opportunities, that revealing one's HIV status will result in public persecution and social stigma, and that the potential for a confidentiality breach will deter those who are at risk from getting tested and seeking medical care.<sup>221</sup> The bottom line for both arguments is that HIV places a person in the category of the "other," "treating that person differently because of a particular distinctive characteristic or set of characteristics that vary from the norm."<sup>222</sup> Not respecting and protecting one's HIV status may negatively affect that individual's physical well being, as well as many other aspects of their life.<sup>223</sup> There must be considerable safeguards in place to prevent information misuse and errant disclosure.<sup>224</sup>

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219. *Id.*

220. *Id.*

221. See discussion *supra* Parts V.A.2-4. Despite the fact that a person's medical information is generally sensitive and private, thought should be given to the diverse composition of the population of HIV infected individuals. Much of this group is composed of already marginalized social groups, such as homosexuals and minorities. See generally Senak, *supra* note 217, at 8. Typically, homosexual political activist groups stress the right to privacy and express concern over the impact the AIDS crisis will have on their further acceptance into mainstream society. *Id.* The rate of HIV infection among minority groups has risen and continues to rise. *Id.* Minorities are inherently marginalized and traditionally mistrustful of the federal government. *Id.* Therefore, some advocates for these groups "vigorously oppose" any effort that would "senselessly drive individuals away from HIV testing and care." Escutia, *supra* note 208, at A2.

222. Senak, *supra* note 217, at 81.

223. *Id.*

224. The Commission stresses California has statutory protections for public health records, which the state has reworked specifically for HIV and AIDS, and state and local health departments must adhere to federal security and confidentiality standards. California Performance Review, *supra* note 7, at 3. California has no documented or reported cases of illegal or inappropriate disclosure of case information from the state's AIDS registry. *Id.* (noting California's lack of documented cases; *but compare* note 214)

## 5. Other Concerns

The Commission points out several technical challenges presented by California's current UI reporting system. Between July 2002 and July 2004, 163,328 laboratory tests were reported to the local health department.<sup>225</sup> Of this total, 26,022 were unmatched, requiring investigation by the local health department to ensure there is no duplication of reported cases.<sup>226</sup> There is a significant backlog of cases pending investigation (12,556 as of July 2004) and the Commission argues the process is "inefficient, burdensome, and expensive" because health care providers do not comply with logs, potential coding errors, and "staff burn-out."<sup>227</sup> Further, cross-referenced logs risk confidentiality because they are necessarily accessible by multiple parties.<sup>228</sup>

An often-unmentioned point of particular concern is the inherent limitation of all HIV case reporting systems. AIDS reporting is fairly complete; nearly all people with AIDS have been diagnosed and the majority of cases are reported within a year.<sup>229</sup> In addition, in-depth data about risk factors and demographics is usually included.<sup>230</sup> An HIV reporting system, however, would provide data only on those individuals who are HIV positive and choose to be tested non-anonymously or to seek HIV-specific health care. This is certainly less than the total population of people infected with HIV.

Also, HIV reporting collects data at the time the infected person is tested, rather than at the point of infection. "HIV diagnosis typically occurs within two years of AIDS diagnosis."<sup>231</sup> Therefore, the data

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225. HIV Reporting in L.A. County, *supra* note 30, at 2.

226. *Id.*

227. *Id.*

228. *Id.* The UI system is "labor intensive, less accurate, and more complex than the name-based system." Carla Rivera, *A Proposal to Track New HIV Cases by Name Instead of Code Could be the Most Vexing Part of a Health System Overhaul*, L.A. TIMES, July 31, 2004, at A24. "California is the only state among the five largest that requires codes for HIV reporting and names for reporting AIDS." *Id.* Those in support of the current system contend that, "even with name reporting, many jurisdictions say they don't have the time to report, so to say this would fix the system completely is false." *Id.*

229. Johri et al., *supra* note 9.

230. *Id.*

231. *Id.* at 3.

collected from HIV reporting would represent HIV infections from merely weeks to several years old. This is likely to reflect differences in the population that are not easily identified or addressed.<sup>232</sup> Though better than none at all, current HIV data is far from ideal. Experts suggest it be “viewed as partial data on HIV prevalence, rather than incidence.”<sup>233</sup> The recommendation stands to “consider what degree of accuracy we need from [HIV] data in order to achieve our aims, and what costs we are willing to incur to do so.”<sup>234</sup>

### *B. Implementing Name-based Reporting in California*

The Commission stresses no additional resources will be needed to make California’s HIV reporting system consistent with its AIDS reporting system.<sup>235</sup> A name-based AIDS reporting system is already in place and the HIV cases will simply be reported by the same database.<sup>236</sup> The Commission predicts the system can change, and all health providers, laboratories, and state and local health departments can fully convert, within six months and current code-based files would be updated within one year.<sup>237</sup> The Commission further proposes that California should require laboratories that monitor CD4+ cell counts report this information as potential unreported AIDS cases, thereby helping California qualify for additional federal funds.<sup>238</sup>

## VI. CONCLUSION

There is a compelling need to monitor HIV infection accurately to provide health officials with the most complete and reliable information about the present incidence and future course of the epidemic. There are, however, considerations regarding an

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232. See generally Escutia, *supra* note 208 (explaining why Latinos may be hesitant to seek early HIV testing).

233. Johri et al., *supra* note 9, at 3.

234. *Id.*

235. California Performance Review, *supra* note 7, at 3.

236. *Id.*

237. *Id.* All records maintained by UI would thus be identified by name as new data are received. *Id.*

238. *Id.* California is one of only thirteen states that do not require it. *Id.*

individual's right to privacy and the health and wellbeing of the community. Therein lays the conflict between name-based versus unique identifier HIV reporting systems.

Both systems are likely to be constitutionally sound, as long as confidentiality provisions are in place and enforced. Though the right to privacy in personal information is not clearly established, the Supreme Court has indicated there is a right to privacy in one's HIV status, though this right may be outweighed by compelling government interests, such as the need for comprehensive HIV surveillance data to protect the greater public health. In this area, an equal protection challenge is unlikely to succeed because people with HIV are not a suspect class and keeping one's HIV status confidential is not a fundamental right.

Currently, California's regulations require that HIV case reports must be made via unique identifier. This method provides a balance between public health and individual privacy interests. The UI system promotes confidentiality, provides a sensitive and informed response to the issues, and offers safeguards against misuse of personal medical information. It also reduces fear of social stigma and deterred or delayed testing because the code cannot readily be traced to patient source. This, in turn, may slow the spread of HIV among those who would otherwise remain unaware of their status.

The federal government has given each state the authority to decide whether to report HIV cases by name or by code and each must do so by undertaking its own analysis of the need for accurate and complete data, as well as the importance of protecting the privacy rights of its citizens. California has chosen, up to this time, to adopt the unique identifier system. The Los Angeles County Commission on HIV Health Services recently concluded this system should be abandoned and name-based HIV reporting system should be implemented because the latter method is more beneficial for the state overall. This proposal was approved in October 2004; the Commission will resume the debate in Sacramento into 2005.