

FOIA MARKER

**This is not a textual record. This is used as an
administrative marker by the William J. Clinton
Presidential Library Staff.**

Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: National AIDS Policy Office

Series/Staff Member: Todd Summers

Subseries:

OA/ID Number: 21089

FolderID:

Folder Title:

Issues - HIV Surveillance-Gostin Article

Stack:

S

Row:

66

Section:

6

Shelf:

3

Position:

1

THE "NAMES DEBATE": THE CASE FOR NATIONAL HIV REPORTING IN THE UNITED STATES*

Lawrence O. Gostin (Hon.)**

James G. Hodge, Jr.***

INTRODUCTION	681
I. THE HISTORICAL DEVELOPMENT OF REPORTING AS A PUBLIC HEALTH PRACTICE.....	689
A. <i>Early Reporting Practices</i>	689
B. <i>The Tensions Between the Practice of Medicine and Public Health</i>	693
C. <i>The Inception of the Modern Epidemic: National AIDS Reporting</i>	695
II. THE CHANGING FACE OF THE AIDS EPIDEMIC	698
A. <i>Developments in Medical Treatment</i>	699
B. <i>Perinatal Transmission</i>	701

* This Article is substantially based on the previously published article, Lawrence O. Gostin et al., *National HIV Case Reporting for the United States—A Defining Moment in the History of the Epidemic*, 337 NEW ENG. J. MED. 1162 (1997), which itself was based on a national consultation on HIV surveillance conducted by the Centers for Disease Control and Prevention [hereinafter CDC] and the Council of State and Territorial Epidemiologists [hereinafter CSTE] held at the Carter Presidential Center in Atlanta, Georgia on May 21-22, 1997. Additional consultations held by the CDC in Atlanta on October 7, 1997 and November 5-6, 1997 also form the basis for this Article. The views expressed by the authors in this Article are not necessarily the views of the CDC, CSTE, or Carter Presidential Center.

** Professor of Law, Georgetown University Law Center; Professor of Law and Public Health, Johns Hopkins University School of Hygiene and Public Health; Co-Director, Georgetown/Johns Hopkins Program on Law and Public Health; CDC Advisory Committee on HIV and STD Prevention.

*** Adjunct Professor of Law, Georgetown University Law Center; Fellow, Greenwall Fellowship Program in Bioethics and Health Policy (supported by the Greenwall Foundation and jointly administered by Georgetown University and Johns Hopkins University). The authors are grateful to Imron Aly, J.D. Candidate (Georgetown University Law Center), Lance Gable, J.D./M.P.H. Candidate (Georgetown/Johns Hopkins Program on Law and Public Health), Karey D'Anna, J.D./M.P.H. Candidate (Georgetown/Johns Hopkins Program on Law and Public Health), and Halimah Delaine, J.D. Candidate (Georgetown University Law Center), for their research assistance. Special thanks to Karen Summerhill, J.D., Research Librarian, Jason Oyler, J.D. Candidate (Georgetown University Law Center), and Darren Hultman, J.D. Candidate (Georgetown University Law Center), and the Edward Bennett Williams Law Library Faculty Services for their research assistance.

C. <i>Effects on Epidemiology</i>	703
III. HIV/AIDS REPORTING: CURRENT STATUS	705
A. <i>AIDS Surveillance</i>	705
B. <i>HIV Surveillance</i>	706
TABLE A: HIV/AIDS REPORTING AMONG STATES AND THE DISTRICT OF COLUMBIA.....	707
IV. PUBLIC HEALTH JUSTIFICATIONS FOR A NATIONAL SYSTEM OF HIV REPORTING	710
A. <i>Monitoring the AIDS Epidemic</i>	712
B. <i>Targeting Prevention and Other Services</i>	713
C. <i>Linking HIV-Infected Persons with Treatment Opportunities, Educational Services, and Partner Notification Support Services</i>	714
D. <i>Just Resource Allocation</i>	716
E. <i>Eligibility for Governmental Benefits</i>	717
V. THE SOCIAL IMPACT OF HIV REPORTING	718
A. <i>The Impact on Voluntary Testing and Treatment: The Importance of Alternative Test Sites</i>	720
B. <i>Discrimination</i>	724
C. <i>Privacy</i>	727
1. <i>Legal Rights to Privacy</i>	728
2. <i>Privacy and Security in the Maintenance and Use of HIV Registries</i>	732
3. <i>Ethical Issues Concerning Privacy</i>	733
VI. THE "NAMES DEBATE": NAMED REPORTING VERSUS UNIQUE IDENTIFIERS	736
CONCLUSION	742

Throughout the States, there have been health and civil approaches that have been most affected. public health measures, notification of the persons to the health powers to subject and treatment, and

Those who have instead, relied on economy, privacy, and argue that respecting human values ease epidemics, giving the right to health's essential to help individuals risk.⁷ Public

¹ This tension can be seen in *Ethics and Public Health* (Steven S. Coughlin ed. 1997) where those of groups lies at the heart of the approach and the just

² See *infra* notes 3 and 4.

³ See Lawrence O. Gostin, *AIDS—Testing, Screening, and Treatment* (1997) (discussing testing, screening, and treatment).

⁴ See Lawrence O. Gostin, *Reflections on Public Health: The Role of Personal Confidentiality in AIDS: Compulsory Testing* 1058 (1989) (critiquing the role of personal confidentiality in AIDS testing).

⁵ See *infra* notes 6 and 7.

⁶ See *infra* notes 8 and 9.

⁷ See Lawrence O. Gostin, *Drug Users: The Threat to Disease Prevention*, 4

.....	703
.....	705
.....	705
.....	706
AND THE	
.....	707
IONAL SYSTEM	
.....	710
.....	712
.....	713
tment	
l Partner	
.....	714
.....	716
.....	717
.....	718
eatment:	
.....	720
.....	724
.....	727
.....	728
nance	
.....	732
.....	733
SUS	
.....	736
.....	742

INTRODUCTION

Throughout the history of contagious diseases in the United States, there has been a basic tension between traditional public health and civil liberties.¹ Proponents of a traditional public health approach have argued that systematic government intervention has been most affective in curtailing disease epidemics.² Traditional public health measures include testing and screening for infection, notification of those at risk of infection, and reporting infected persons to the health department.³ The health department is also empowered to subject individuals to mandatory medical examinations and treatment, directly observed therapy, isolation, or quarantine.⁴

Those who have opposed traditional public health powers have, instead, relied on policies that optimally protect individual autonomy, privacy, and liberty.⁵ Adherents to a civil liberties approach argue that respect for rights and freedoms represents a transcending human value. A civil liberties perspective in the context of disease epidemics tends to focus on well-informed individuals exercising the right to self determination.⁶ Under this view, public health's essential functions are to provide education and counseling to help individuals to make more informed decisions to reduce their risk.⁷ Public health should also provide the means for self-

¹ This tension can be expressed in ethical, as well as practical terms. See Marc Lappe, *Ethics and Public Health*, in *ETHICS IN EPIDEMIOLOGY AND CLINICAL RESEARCH* 183, 183 (Steven S. Coughlin ed., 1995) ("A fundamental tension between the rights of individuals and those of groups lies at the core of many ethical public health dilemmas.")

² See *infra* notes 53-87 and accompanying text (discussing the traditional public health approach and the justification theory).

³ See Lawrence O. Gostin et al., *The Case Against Compulsory Casefinding in Controlling AIDS—Testing, Screening and Reporting*, 12 *AM. J.L. & MED.* 7, 7-47 (1987) (examining the testing, screening, and reporting programs and assessing their legal and policy justifications).

⁴ See Lawrence O. Gostin, *The Resurgent Tuberculosis Epidemic in the Era of AIDS: Reflections on Public Health, Law, and Society*, 54 *MD. L. REV.* 1, 112-29 (1995) (discussing the role of personal control in the tuberculosis epidemic); see also Larry Gostin, *The Politics of AIDS: Compulsory State Powers, Public Health, and Civil Liberties*, 49 *OHIO ST. L.J.* 1017, 1058 (1989) (critiquing compulsory public health powers).

⁵ See *infra* notes 226-32 and accompanying text (setting forth the argument against the traditional public health approach).

⁶ See *infra* notes 226-32 and accompanying text (arguing that sufficient dissemination of information will effectively shape behavioral practices).

⁷ See Lawrence O. Gostin & Zita Lazzarini, *Prevention of HIV/AIDS Among Injection Drug Users: The Theory and Science of Public Health and Criminal Justice Approaches to Disease Prevention*, 46 *EMORY L.J.* 587, 592 (1997) (noting that current strategies to reduce

protection such as condoms for persons who engage in sex and sterile syringes for those who inject illegal drugs.⁸

This historical tension between civil liberties and public health has sharpened in the modern HIV epidemic. To many (particularly ideological conservatives) the pendulum has swung decidedly in favor of civil liberties and against public health.⁹ This view, often referred to as "AIDS Exceptionalism,"¹⁰ holds that traditional public health policies that have long been effective in reducing epidemic disease are not used in curtailing HIV infection.¹¹ The explanation offered is that public health officials have deferred to civil libertarians and community activists, thus failing to take measures known to prevent disease transmission.¹²

This characterization of the modern HIV epidemic is misplaced because it relies on at least two unproved assumptions. First, AIDS exceptionalists assume that traditional public health measures such as compulsory testing, partner notification, and reporting have been historically effective and would continue to be effective if rou-

tinely applied in the past, then, and other responses.

Second, AIDS exceptionalists assume that traditional public health measures have been effective in reducing epidemic disease.¹⁴ In fact, it is possible that the measures have been ineffective, thus jeopardizing public health and undermining the effectiveness of the epidemic response. The epidemic response and human rights are considered an essential part of the epidemic response, then, embrace the intrinsic value of the epidemic response.

The historical tension between civil liberties and public health is a central issue in the AIDS epidemic. Mandatory reporting of AIDS to local health departments is a public health measure that has been effective in reducing the spread of the disease.¹⁵ Even

the harm to injection drug users embraces education counseling, and the means for safer injection practices).

⁸ See *id.* (arguing that physicians should be permitted to write prescriptions for syringes, pharmacists should be authorized to sell syringes over the counter, and syringe exchange programs should be legalized and funded).

⁹ See Chandler Burr, *The AIDS Exception: Privacy vs. Public Health*, ATLANTIC MONTHLY, June 1997, at 57 (arguing that traditional public health measures have been vacated in dealing with HIV in favor of the accommodation of civil rights concerns).

¹⁰ See Ronald Bayer, *Public Health Policy and the AIDS Epidemic: An End to HIV Exceptionalism?*, 324 NEW ENG. J. MED. 1500, 1501 (1991) (arguing that those who advocated AIDS exceptionalism dominated public discourse with respect to the disease); Burr, *supra* note 9, at 58 ("What is known in the field of public health as AIDS exceptionalism has been maintained in legally and programmatically direct ways and also in complex and subtle ways.").

¹¹ See Bayer, *supra* note 10, at 1500 ("[I]n the first decade of the AIDS epidemic, an alliance of gay leaders, civil libertarians, physicians, and public health officials began to shape a policy for dealing with AIDS that reflected the exceptionalists perspective."); Scott Burris, *Public Health, "AIDS Exceptionalism" and the Law*, 27 J. MARSHALL L. REV. 251, 272 (1994) (explaining that AIDS is not really "exceptional" when compared to the similar response received by diseases that become "important").

¹² See Marcia Angell, *A Dual Approach to the AIDS Epidemic*, 324 NEW ENG. J. MED. 1498, 1499 (1991) (suggesting that a dual approach, distinguishing social from epidemiological problems is necessary); Bayer, *supra* note 10, at 1500-01 (noting that public health traditionalists advocated to have AIDS and HIV brought under the existing statutory provisions to control the spread of disease); Tom A. Coburn, *Forum: Is It Time To Treat HIV Like All Other STDs?*, WASH. POST., Nov. 4, 1997, at H23 ("We know enough about [HIV] to prevent its spread, but we haven't done so because . . . we have abandoned the public-health procedures that have successfully curtailed other STDs.").

¹³ See Bayer, *supra* note 10, at 1500 (discussing future public health measures).

¹⁴ See Angell, *supra* note 12, at 1499 (discussing the tradition of public health).

¹⁵ See *infra* notes 16-17 (discussing statistical reporting).

¹⁶ See *infra* note 17 (discussing modern public health).

¹⁷ See LAWRENCE, *supra* note 1, at 149 (discussing AIDS PANDEMIC and public health in the *Human Rights*, 1 J. HUMAN RIGHTS 1 (1997)).

¹⁸ See Centers for Disease Control and Prevention, *Information for Effective Communication*, 207, 208 (1992) (tracture).

¹⁹ See Stephen J. Conroy, *Public Health Surveys* (noting that in 1743).

sex and ster-

public health
y (particularly
decidedly in fa-
view, often re-
ditional public
acing epidemic
he explanation
civil libertari-
asures known

c is misplaced
s. First, AIDS
alth measures
reporting have
effective if rou-

means for safer in-

ptions for syringes,
d syringe exchange

Health, ATLANTIC
ures have been va-
ncerns).

End to HIV Excep-
ose who advocated
isease); Burr, *supra*
ptionalism has been
complex and subtle

S epidemic, an alli-
als began to shape a
ive."); Scott Burris,
LEV. 251, 272 (1994)
similar response re-

NEW ENG. J. MED.
l from epidemiologi-
public health tradi-
statutory provisions
Treat HIV Like All
ut [HIV] to prevent
public-health proce-

tinely applied in the AIDS epidemic.¹³ Even if they were effective in the past, there exists distinct dissimilarities between HIV/AIDS and other infectious diseases that may justify differential responses.

Second, AIDS exceptionalists assume that traditional governmental interventions will have no adverse effects on populations at risk of disease.¹⁴ However, by violating the right to autonomy and privacy, it is possible that persons at risk of HIV disease would be dissuaded from constructive engagement with public health and medicine, thus jeopardizing the health of communities.¹⁵ Modern public health professionals often believe that coercive strategies would undermine their efforts to prevent risk behaviors, and would drive the epidemic underground.¹⁶ According to this view, public health and human rights are mutually reinforcing; affording rights and dignity to women, injecting drug users, gay men, and others, is considered an essential public health strategy.¹⁷ Public health officials, then, embrace a civil liberties approach not necessarily for the intrinsic value of human freedom, but because it is necessary for optimal health outcomes for populations.

The historical divisiveness between traditional public health and civil liberties can perhaps best be illustrated by disease reporting. Mandatory reporting of diseases predated the founding of the republic.¹⁸ A Rhode Island statute of 1741 required tavern keepers to report to local authorities any patrons known to harbor contagious diseases.¹⁹ Ever since, disease reporting has been ubiquitous, a

¹³ See Bayer, *supra* note 10, at 1503-04 (arguing that these measures effectively could address future public health problems as well as AIDS).

¹⁴ See Angell, *supra* note 12, at 1499 (ignoring the potential counterproductivity associated with the traditional public health approach).

¹⁵ See *infra* notes 241-45 (noting that the lack of anonymity may reduce the accuracy of statistical reporting).

¹⁶ See *infra* note 237 and accompanying text (setting forth the assumptions underlying the modern public health argument).

¹⁷ See LAWRENCE O. GOSTIN & ZITA LAZZARINI, HUMAN RIGHTS AND PUBLIC HEALTH IN THE AIDS PANDEMIC xiv-xv (1997) (arguing that "human rights are as serious and integral as public health in the fight against the AIDS pandemic"); Jonathan Mann et al., *Health and Human Rights*, 1 J. HEALTH & HUM. RTS. 7, 13 (1994) (stating that violations of health and human rights often include violations which have a negative impact on health).

¹⁸ See Centers for Disease Control & Prevention, *The Role of Public Health Surveillance: Information for Effective Action in Public Health*, 41 MORBIDITY & MORTALITY WKLY. REP. 207, 208 (1992) (tracing the roots of public health surveillance back to the seventeenth century).

¹⁹ See Stephen B. Thacker, *Historical Development*, in PRINCIPLES AND PRACTICE OF PUBLIC HEALTH SURVEILLANCE 3, 4 (Steven M. Teutsch & R. Elliott Churchill eds., 1994) (noting that in 1743, "the colony passed a broader law requiring the reporting of small pox,

standard method of public health surveillance that is adopted for nearly fifty modern health conditions.³⁰ Reporting is considered essential to public health because it enables reliable tracking and investigation of the incidence and prevalence of disease.³¹ Consequently, it is thought to provide a scientific basis for prevention activities, targeting of resources, and links to counseling and health services.³²

Reporting, however, is deeply troubling to individuals, communities, civil libertarians, and to a certain extent, the medical profession.³³ Reporting requires notification of a person's name, identifying personal characteristics, health status, and risk behaviors to government.³⁴ Government maintains this highly sensitive information in paper files and, more recently, in computer databases.³⁵ Named reporting also by its nature requires a breach of the therapeutic relationship, because the physician, by law, must report confidential information to the health department.³⁶ It is for this rea-

son that medical reporting.²⁷

The HIV/AIDS use of "named" social controversy first requirement early public health ignited a firestorm gay organizations not trust the government were concerned personal privacy insurance. "Named" politics. The "have died of AIDS" government would with this stigma.

Critics, on the reluctance of physicians of named HIV/AIDS ally all significant in the United States require the collection of infection.³⁴ of adults and representing a

yellow fever, and cholera"); Lawrence O. Gostin et al., *The Public Health Information Infrastructure: A National Review of the Law on Health Information Privacy*, 275 JAMA 1921, 1921 (1996) (adding that by 1850, the first year of the decennial census the federal government began to publish nationwide data on mortality); JAMES A. TOBEY, PUBLIC HEALTH LAW 11 (1926) (referring to a similar Rhode Island law passed in 1721, 20 years prior to the date reported by other authors).

³⁰ See Terence L. Chorbha et al., *Mandatory Reporting of Infectious Diseases by Clinicians*, 262 JAMA 3018, 3018 (1989) (noting that all states and territories of the United States report data for 49 infectious diseases); Nancy E. Stroup et al., *Sources of Routinely Collected Data for Surveillance*, in PRINCIPLES AND PRACTICE OF PUBLIC HEALTH SURVEILLANCE, *supra* note 19, at 31, 33 ("In at least one state, however, reporting was required for over 160 infectious diseases or related conditions, 90 occupational diseases, 23 other environmental diseases, 29 congenital or related conditions, and 6 diseases of unknown cause.").

³¹ See Bayer, *supra* note 10, at 1500 (noting that reporting of infected persons was a conventional public health approach).

³² See Coburn, *supra* note 12, at 423 (arguing that reporting is critical to long term AIDS strategies); see also *infra* notes 124-28 (discussing some of the treatment benefits derived from reporting).

³³ See Bayer, *supra* note 10, at 1501 (discussing groups such as physicians and civil libertarians who opposed a traditional public health approach).

³⁴ See Department of Health and Human Services, Adult HIV/AIDS Confidential Case Report (Doc. No. CDC50.42A) (on file with author).

³⁵ See Lawrence O. Gostin, *Health Information Privacy*, 80 CORNELL L. REV. 451, 457 (1995) (discussing governmental storage procedures).

³⁶ See Centers for Disease Control, *Update: Public Health Surveillance for HIV Infection—United States, 1989 and 1990*, 39 MORBIDITY & MORTALITY WKLY. REP. 853, 859-61 (1990); see also Lawrence O. Gostin & James G. Hodge, Jr., *Piercing the Veil of Secrecy in HIV/AIDS and Other Sexually Transmitted Diseases: Theories of Privacy and Disclosure in Partner Notification*, 5 DUKE J. GENDER L. & POL'Y (forthcoming 1998).

²⁷ See Daniel M. L. CENTER REP., Dec. 19

²⁸ See RONALD BA PUBLIC HEALTH 116-

²⁹ See *infra* Part V

³⁰ See BAYER, *sup* number of people see

³¹ Registries involve individuals over time, assuring individuals are counted

³² See Bayer, *sup* HIV is indicative of the HIV).

³³ See generally P. *prehensive State-By-State* (comprehensive summary of cases).

³⁴ See generally *id.*

adopted for
considered es-
eking and in-
se.³¹ Conse-
r prevention
g and health

ls, communi-
dical profes-
ame, identi-
behaviors to
isitive infor-
databases.³⁵
of the thera-
t report con-
for this rea-

formation *Infra*-
275 JAMA 1921,
e federal govern-
LIC HEALTH LAW
prior to the date

es by Clinicians,
United States re-
utinely Collected
EILLANCE, *supra*
r over 160 infec-
virological dis-
).

ersons was a con-

long term AIDS
benefits derived

is and civil liber-

onfidential Case

A. REV. 451, 457

e for HIV Infec-
REF. 853, 859-61
'eal of Secrecy in
nd Disclosure in

son that medical organizations have historically resisted disease reporting.²⁷

The HIV/AIDS epidemic has engendered a heated debate about the use of "names."²⁸ HIV reporting has evoked bitter political and social controversy and impassioned community resistance.²⁹ The first requirement for named HIV reporting, in Colorado, and the early public health proposals for HIV surveillance in the mid-1980s ignited a firestorm of community protest.³⁰ Civil libertarians and gay organizations opposed named HIV reporting because they did not trust the government to maintain sensitive registries³¹ and they were concerned about political retribution, potential invasions of personal privacy, and discrimination in employment, housing, and insurance. "Names" have always been a powerful symbol in AIDS politics. The "names" quilt has systematically honored persons who have died of AIDS, and it was at one time unthinkable that government would collect, store, and use the identities of persons living with this stigmatic infection.

Critics, on the other hand, have reacted with incredulity at the reluctance of public health officials to implement a national system of named HIV reporting.³² Named reporting is required for virtually all significant sexually transmitted and communicable infections in the United States.³³ Most reporting laws, moreover, require the collection of names, and notification at the earliest stages of infection.³⁴ By contrast, only thirty-one states require reporting of adults and adolescents who test positive for the HIV antibody, representing a relatively small portion of all cases of HIV infec-

²⁷ See Daniel M. Fox, *From TB to AIDS: Value Conflicts in Reporting Disease*, HASTINGS CENTER REP., Dec. 1986, at 11 (discussing the dilemma in disease reporting).

²⁸ See RONALD BAYER, *PRIVATE ACTS, SOCIAL CONSEQUENCES: AIDS AND THE POLITICS OF PUBLIC HEALTH* 116-23 (1989) (outlining the evolution of public health reporting).

²⁹ See *infra* Part V (analyzing the social impacts of reporting, particularly discrimination).

³⁰ See BAYER, *supra* note 28, at 118-23 (noting that there was a marked decrease in the number of people seeking treatment in Colorado after mandatory reporting was imposed).

³¹ Registries involve the collection and consolidation of epidemiologic data about individuals over time, assuring the identification of each new case and eliminating the chance that individuals are counted more than once. See Stroup et al., *supra* note 20, at 51.

³² See Bayer, *supra* note 10, at 1501 (noting that the demand for reporting with respect to HIV is indicative of the sentiment that the effective approaches of the past are appropriate to HIV).

³³ See generally Paul Barron et al., *State Statutes Dealing with HIV and AIDS: A Comprehensive State-By-State Summary*, 5 LAW & SEXUALITY 1, 3 (1995) (containing a comprehensive summary of state legislation related to HIV, AIDS, and sexually transmitted diseases).

³⁴ See generally *id.*

tion.³⁵ Why, it is repeatedly asked, do public health officials shy from adopting policies concerning HIV/AIDS that they have not hesitated to use for most other diseases?

We have long opposed named HIV reporting for many of the same reasons offered by the community of persons living with HIV/AIDS.³⁶ HIV infection, however, was at one time quite distinct from other infectious diseases. There were strong and justifiable reasons for rejecting named reporting: HIV infection was not transmissible through the air like tuberculosis; it was not treatable like hepatitis; and persons could not be rendered non-infectious as they could with syphilis or gonorrhea.³⁷ HIV/AIDS was also unique because it engendered the kinds of fear and associated discrimination that demanded privacy and respect for human rights. We have changed our mind about named HIV reporting, not because we have changed, but because the epidemic has changed. We value civil liberties but, perhaps more important, we value the health and lives of persons living with HIV/AIDS.

Our nation's surveillance system has to date relied on reporting patients with AIDS as defined by the Centers for Disease Control and Prevention (CDC). AIDS reporting focuses on the most advanced stages of HIV disease, which, in the absence of effective treatment, develop on average ten years after initial infection.³⁸ Consequently, the AIDS reporting system provides a snapshot of a decade-old epidemic. Innovative antiretroviral therapies are now further delaying the progression of HIV disease, thus significantly affecting trends in AIDS reporting.³⁹ The compelling need for accurate monitoring of HIV infection and for effective medical and public health interventions mandates a fundamental reevaluation of AIDS surveillance. In this Article, we present the case for a national system of named HIV reporting in the United States.

This Article systematically examines the public health benefits and the individual burdens presented by a national system of

named HIV re-
of disease repo
reporting, stemn
Middle Ages,⁴²
times are disc
reporting is well
health function

Part II expla
cerning the H
medical treatn
als to remain
nite periods of
long life ex)
infectiousness.
cally reduces
These and oth
effects.

Part III prov
system for mo
velopment of
politically cha
emerged. Th
HIV/AIDS rep

In Part IV,
that America
porting.⁴⁸ A s
duce many be
improved mon
prevention ar
positive persc
services, inclu
resource alloc:

³⁵ See *infra* notes 161-87 and accompanying text (discussing the analytical breakdown of this reporting).

³⁶ One of us (Lawrence O. Gostin) testified against HIV reporting when the issue was first being considered in Colorado in 1984.

³⁷ See generally Steven Eisenstat, *An Analysis of the Rationality of Mandatory Testing for the HIV Antibody: Balancing the Governmental Public Health Interests with the Individual's Privacy Interest*, 52 U. PITT. L. REV. 327, 329-35 (1991) (discussing HIV).

³⁸ See Josephine Gittler & Sharon Rennert, *HIV Infection Among Women and Children and Antidiscrimination Laws: An Overview*, 77 IOWA L. REV. 1313, 1315 (1992) (explaining the progressive nature of HIV infection).

³⁹ See *infra* text accompanying note 131; Part II.C.

⁴⁰ See *infra* note

⁴¹ See Thacker,
back to the period c

⁴² See *infra* note

⁴³ See *infra* not-
vances with respect

⁴⁴ See *infra* note

⁴⁵ See *infra* note,

⁴⁶ See *infra* note

⁴⁷ See Tbl. A.

⁴⁸ See *infra* note

named HIV reporting. Part I discusses the historical development of disease reporting as a public health practice.⁴⁰ The origins of reporting, stemming back to early surveillance techniques during the Middle Ages,⁴¹ through the founding of the republic, to modern times are discussed. This section demonstrates that disease reporting is well established and an integral part of essential public health functions.

Part II explains the major changes in science and medicine concerning the HIV/AIDS epidemic.⁴² Fundamental developments in medical treatment now make it possible for HIV-infected individuals to remain healthy, without serious symptomatology for indefinite periods of time.⁴³ This has the potential to considerably prolong life expectancy and, perhaps, to significantly reduce infectiousness.⁴⁴ Medical treatment of pregnant mothers dramatically reduces the probabilities of perinatal HIV transmission.⁴⁵ These and other developments have demonstrable epidemiological effects.

Part III provides a factual description of the current surveillance system for monitoring the modern HIV/AIDS epidemic.⁴⁶ The development of the AIDS reporting system is discussed, noting the politically charged environment in which the "names debate" has emerged. This part also provides the most recent data about HIV/AIDS reporting practices in the fifty states.⁴⁷

In Part IV, we present a number of justifications for our thesis that America should develop a national system of named HIV reporting.⁴⁸ A sophisticated system of HIV surveillance ought to produce many benefits to individuals and populations, including: (1) improved monitoring of the epidemic; (2) enhanced ability to target prevention and other public health services; (3) linking HIV-positive persons with treatment opportunities and educational services, including partner notification support services; (4) fairer resource allocation; and (5) equitable determination of eligibility of

⁴⁰ See *infra* notes 53-87 and accompanying text.

⁴¹ See Thacker, *supra* note 19, at 3 (tracing the first public health surveillance system back to the period of the bubonic plague).

⁴² See *infra* notes 123-60 and accompanying text.

⁴³ See *infra* notes 123-28 and accompanying text (discussing the impact of medical advances with respect to prevention and treatment of HIV/AIDS).

⁴⁴ See *infra* notes 123-28 and accompanying text.

⁴⁵ See *infra* notes 146-51 and accompanying text.

⁴⁶ See *infra* notes 161-87 and accompanying text.

⁴⁷ See Tbl. A.

⁴⁸ See *infra* notes 188-225 and accompanying text.

infected individuals for government benefits. We are not suggesting that HIV reporting will be unequivocally beneficial or that it will be very effective in each of the foregoing areas. HIV reporting alone, is not a panacea for the multi-dimensional problems arising from the AIDS epidemic. Yet, HIV reporting is likely to contribute to each of the benefits discussed in this part of the Article.

From a public health perspective, there has always been one serious potential objection to HIV reporting. Would the social impact of such a system be so detrimental that individuals would fail to be tested and cooperatively engage in the health care and public system? Part V examines the potential effect of HIV reporting on voluntary testing and treatment and discrimination.⁴⁹ While there remains a great deal of social stigma and discrimination against persons living with HIV/AIDS, America is much changed from the early days of the HIV epidemic. Remaining social concerns about testing rates and discrimination stem from the same fundamental concern, that privacy interests of persons living with HIV/AIDS must be preserved to the greatest extent possible.

In truth, most people (even most community activists and civil libertarians) now agree that HIV reporting is necessary for public health purposes.⁵⁰ Yet, could HIV surveillance be conducted as well, or better, without the use of a person's name? This becomes the central intellectual issue in the "names debate." In Part VI, we critically examine the case for unique identifiers (UIs).⁵¹ After examining the evidence from Maryland and Texas, the only two states to engage in a UI system,⁵² we conclude that at this time UIs would not provide sufficiently reliable data. We also observe that a UI system could actually create greater risks to privacy than a name-based system.

I. THE HISTORY

The history of public health surveillance is "the ongoing, systematic data on specific from the early and prevent control. Crude forms of terring the population requiring proper supplies.⁵³ With counts and more statistical methods health practice the foundations

William Farr's concept of surveillance

⁴⁹ Centers for Disease Control (CDC) surveillance).

⁵⁴ See Thacker, *et al.*, analyzing them, and things for that matter. The occasions for indeistic beliefs into the CLIFFORD ALLCHIN (and methods of epidemic

⁵⁵ See Thacker, *et al.*

⁵⁶ Through his testimony, John Graunt is (through the record *Public Health Surveillance* et al. eds., 1997) band Captain and history, entry dated March attributed to Sir William Farr from the bills of mortality.

⁵⁷ See Thacker, *et al.*, the 1700s in Europe methods concerning

⁵⁸ Berkelman et al. William Farr as a pioneer

⁴⁹ See *infra* notes 226-320 and accompanying text.

⁵⁰ See *infra* note 321 and accompanying text (noting agreement among gay and civil liberties groups that reporting is necessary).

⁵¹ See *infra* notes 321-61 and accompanying text.

⁵² See *As AIDS Cases Wane, Pressure Grows for Reporting HIV Infections*, 12 AIDS Pol'y & L. (BNA) 1, 10-11 (Oct. 3, 1997) (noting that both Maryland and Texas use a unique identifier system).

I. THE HISTORICAL DEVELOPMENT OF REPORTING AS A PUBLIC HEALTH PRACTICE

A. Early Reporting Practices

The history of reporting is internally connected to the history of public health surveillance. Modern public health surveillance, or "the ongoing, systematic collection, analysis, and interpretation of data on specific health events" for public health uses,⁵³ originates from the early development of governmental activities to control and prevent communicable diseases during the late Middle Ages.⁵⁴ Crude forms of monitoring illnesses led to societal regulations deterring the polluting of public thoroughfares and water supplies, requiring proper burials, and implementing safer handling of food supplies.⁵⁵ With the application of numerical analysis to death counts and mortality in Europe in the 1660's⁵⁶ and the advent of statistical methods of analysis a century later,⁵⁷ pioneers of public health practice in Europe and the United States developed some of the foundations for modern surveillance in the nineteenth century.

William Farr, often recognized as "the founder of the modern concept of surveillance,"⁵⁸ systematically collected, evaluated, and re-

⁵³ Centers for Disease Control & Prevention, *supra* note 18, at 207 (defining public health surveillance).

⁵⁴ See Thacker, *supra* note 19, at 3 ("The idea of observing, recording, and collecting facts, analyzing them, and considering reasonable courses of action," about diseases [or any other things for that matter] stems from the philosophical and medical teachings of Hippocrates). The occasions for investigation of epidemic diseases until this time were often obviated by deistic beliefs into the causes of such epidemics and the divine origin of their cessation. See CLIFFORD ALLCHIN GILL, *THE GENESIS OF EPIDEMICS* 12-13 (1928) (reviewing the techniques and methods of epidemiological science).

⁵⁵ See Thacker, *supra* note 19, at 3.

⁵⁶ Through his treatise in 1662, *Natural and Political Observations on the Bills of Mortality*, John Graunt is generally recognized as the first individual to use numerical methods (through the recording of deaths) to monitor public health. See Ruth L. Berkelman et al., *Public Health Surveillance*, in 2 OXFORD TEXTBOOK OF PUBLIC HEALTH 735, 735 (Roger Detels et al. eds., 1997); cf. GILL, *supra* note 54, at 18 ("Captain John Graunt, F.R.S., a trainband Captain and haberdasher of London, was not, according to John Evelyn ('Evelyn's Diary,' entry dated March 22, 1675), the real author of [the above-referenced] book, which is attributed to Sir William Petty, who, he states, is 'the author of the ingenious deductions from the bills of mortality which go under the name of Mr. Graunt.'").

⁵⁷ See Thacker, *supra* note 19, at 4 (noting forms of public health surveillance began in the 1700s in Europe and the United States). For a discussion of the perils of early statistical methods concerning epidemiology, see GILL, *supra* note 54, at 18-24.

⁵⁸ Berkelman et al., *supra* note 56, at 735; see Thacker, *supra* note 19, at 4 (describing William Farr as a prominent name in the development of public health surveillance activities).

ported data on vital statistics as Superintendent of the Statistical Department of the General Registrar's Office of England and Wales from 1839 to 1879.⁵⁹ Farr spoke on the utility of surveillance:

[Morbidity registration] will be an invaluable contribution to therapeutics, as well as to hygiene, for it will enable the therapeutists 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.⁶⁰

Farr's work was furthered in Europe by Edwin Chadwick, also of the United Kingdom, who researched environmental causes of disease and Louis Villerme who linked poverty with factors of mortality in Paris.⁶¹

In the United States, surveillance practices including reporting stem back to colonial law.⁶² By the middle of the nineteenth century, significant strides had been made. Lemuel Shattuck related mortality and communicable diseases to living conditions in his influential 1850 report of the Massachusetts Sanitary Commission.⁶³ Shattuck recommended state-supported collection of health data "by age, gender, occupation, socioeconomic level, and locality."⁶⁴ That same year, the federal government began publishing its first national mortality statistics based on the decennial census.⁶⁵ Within the next thirty years, morbidity data began to be organized and collected by state and federal governments.⁶⁶ National morbidity data collection on several infectious diseases began as early as 1878 in the United States.⁶⁷

⁵⁹ See Berkelman et al., *supra* note 56, at 735 (discussing William Farr's accomplishments and efforts within the history of public health surveillance); Thacker, *supra* note 19, at 4 (same).

⁶⁰ MILTON J. ROSENAU, PREVENTIVE MEDICINE AND HYGIENE 1002 (1917) (explaining the usefulness of morbidity registration).

⁶¹ See Berkelman et al., *supra* note 56, at 735 (discussing how William Farr's efforts at health monitoring were extended in the nineteenth century).

⁶² See *supra* text accompanying note 19 (stating that disease reporting has been a standard method of public health surveillance since 1741).

⁶³ See Berkelman et al., *supra* note 56, at 735; Thacker, *supra* note 19, at 4.

⁶⁴ Thacker, *supra* note 19, at 4.

⁶⁵ See *id.*

⁶⁶ See *id.* Massachusetts first implemented a voluntary reporting system of prevalent diseases in 1874. See *id.*

⁶⁷ See Berkelman et al., *supra* note 56, at 735 (noting that collection of nationwide morbidity data for diseases such as small pox and yellow fever was initiated in the United States in 1878); see also Thacker, *supra* note 19, at 4-5 (noting that Congress authorized the fore-

Increased de
greater organi
techniques beg
infectious dise
menting surve
information,⁷⁰
on physicians
program of cor
Europe), for se
member states
which gathered
demic diseases

In the Unite
statutes of var

runner of the Public
time for diseases inc

⁶⁸ See, e.g., ROSE
tistics "has been fel
in turn has been ac
tality statistics").

⁶⁹ See Berkelman
concepts of public h

⁷⁰ See Berkelman
surveillance is that
health data."); see
for the control of c
knowledge of how,
note 60, at 1002-03
found that it is in
when, where, and
note 19, at 109 ("Pr
first requisites of a

⁷¹ See, e.g., ROS
data for morbidity
Communicable Dis
(1931) [hereinafter
and reporting of co
cians must rest th
individual case.]).
Michigan in 1893.
reporting since 174

⁷² See Berkelman

⁷³ See *id.* at 736

⁷⁴ See TOBEY, s
forth in state laws
required differ in
the reporting of in
widely, as do also t

the Statistical
and Wales
surveillance:

tribution to
enable the
ality of all
lackery . . .
ffering di-

dwick, also of
causes of dis-
eases of mortal-

ling reporting
nineteenth cen-
attack related
ions in his in-
Commission.⁶³
f health data
nd locality."⁶⁴
shing its first
ial census.⁶⁵
, be organized
National mor-
egan as early

s accomplishments
upra note 19, at 4

7) (explaining the
n Farr's efforts at
z has been a stan-
t 4.

m of prevalent dis-

f nationwide mor-
the United States
thorized the fore-

Increased development and reliance on morbidity data led to greater organization of public health departments.⁶⁸ Surveillance techniques began to focus on detecting and controlling the spread of infectious disease.⁶⁹ A key component toward successfully implementing surveillance systems was the effective gathering of health information,⁷⁰ primarily through reporting requirements imposed on physicians and laboratories.⁷¹ The United Kingdom began a program of compulsory reporting, (or notification as it is known in Europe), for selected diseases in 1899.⁷² By 1907, several European member states organized the International Office of Public Hygiene which gathered and published information on the prevalence of epidemic diseases.⁷³

In the United States, many states passed mandatory reporting statutes of varying application.⁷⁴ These laws often generalized the

runner of the Public Health Service in 1878 to collect such data for use in matters of quarantine for diseases including cholera, smallpox, plague, and yellow fever).

⁶⁸ See, e.g., ROSENAU, *supra* note 60, at 1002 (remarking that the need for morbidity statistics "has been felt only with the advent of present day public health administration, which in turn has been activated in large measure by the story of the causes of death told by mortality statistics").

⁶⁹ See Berkelman et al., *supra* note 56, at 735 (describing public health activities in which concepts of public health surveillance evolved); Thacker, *supra* note 19, at 4 (same).

⁷⁰ See Berkelman et al., *supra* note 56, at 735 ("A critical component of the definition of surveillance is that surveillance systems include the ongoing collection, analysis, and use of health data."); see also MARK F. BOYD, PREVENTIVE MEDICINE 145 (1932) ("Modern methods for the control of communicable disease require that the health authorities have a prompt knowledge of how, when, and where cases of . . . diseases are occurring."); ROSENAU, *supra* note 60, at 1002-03 (stating that "[t]hose responsible for public health administration have found that it is impossible to effectively control a disease without prompt information of when, where, and under what conditions cases of the disease are occurring"); TOBEY, *supra* note 19, at 109 ("Prompt notification of the existence of a communicable disease is one of the first requisites of adequate control.").

⁷¹ See, e.g., ROSENAU, *supra* note 60, at 1007-10 (analyzing physicians' roles in collecting data for morbidity statistics); Report of the Committee on Communicable Disease Control, Communicable Disease Control, White House Conference on Child Health and Protection 4-5 (1931) [hereinafter Communicable Disease Control] (on file with author) ("The recognition and reporting of communicable diseases is the first step towards control. . . . On the physicians must rest the special responsibility for the authoritative, immediate reporting of the individual case."). The first state to require reporting of certain infectious diseases was Michigan in 1893. See Thacker, *supra* note 19, at 5 (describing the progression of disease reporting since 1741).

⁷² See Berkelman et al., *supra* note 56, at 735.

⁷³ See *id.* at 736 (discussing the history of public health surveillance in Europe).

⁷⁴ See TOBEY, *supra* note 19, at 109 (noting that reporting requirements are usually set forth in state laws); see also BOYD, *supra* note 70, at 145 ("The diseases whose notification is required differ in various jurisdictions."); ROSENAU, *supra* note 60, at 1003-04 (concerning the reporting of infectious diseases, "[t]he laws and regulations of the several States differ widely, as do also the efforts made to enforce them").

classes of disease to be reported.⁷⁵ Classifications of reportable conditions included cases of contagious, infectious, or communicable disease, as well as "all diseases dangerous to the public health."⁷⁶ Some state legislatures deferred to the judgment of state health departments to decide which diseases should be reported.⁷⁷ Only later did states begin to delineate specific diseases for which reporting was required.⁷⁸ Reporting practice in the early twentieth century generally involved the circulation of notification cards by state or local health departments to physicians.⁷⁹ The "standard notification blank"⁸⁰ required physicians to provide the patient's name, age, sex, race, local address, occupation, and occupational address together with the disease or "suspected disease," the date of diagnosis, and the physician's signature and address.⁸¹ These cards were mailed to local or state health authorities for verification, documentation, and data analysis.⁸²

Reporting requirements differed extensively across jurisdictions in the United States, making national disease monitoring tenuous at best.⁸³ A model reporting law circulated by the United States Public Health Service as early as 1913⁸⁴ in an attempt to homogenize reporting requirements for communicable and occupational diseases was passed by only a few states.⁸⁵ Not until 1925 did all states report occurrences of certain infectious diseases to the United States Public Health Service.⁸⁶ Yet, over the next several

decades, better
creasingly sophis-
tication of mor-
bid epidemic disea-

B. The Ten

As mandato-
points of publi-
c tension arose
Public health
reporting danger
since reporting
cians, public
tion.⁹¹ Physi-
cians, public
dividual patier
to produce th
breaching the
and patients.⁹³
itly perpetuate

⁷⁵ See ROSENAU, *supra* note 60, at 1004 (noting the differences in categories of diseases within the laws and regulations of several states).

⁷⁶ *Id.*

⁷⁷ See Thacker, *supra* note 19, at 5.

⁷⁸ See, e.g., BOYD, *supra* note 70, at 145-46 (listing diseases included in standard morbidity law); ROSENAU, *supra* note 60, at 1004-05 (same); TOBEY, *supra* note 19, at 109 (same).

⁷⁹ See ROSENAU, *supra* note 60, at 1012; see also BOYD, *supra* note 70, at 496-500.

⁸⁰ ROSENAU, *supra* note 60, at 1012.

⁸¹ *Id.* (noting that this standard form was approved in 1913 by the state and territorial health authorities and the United States Public Health Service). Compare the information required in this form with that required in modern CDC HIV/AIDS reports. See *infra* text accompanying notes 108-87 (discussing the differences in modern reporting requirements and the differing issues arising therefrom).

⁸² See ROSENAU, *supra* note 60, at 1012 (noting the purpose of the reports is to allow "proper measures [to] be taken to prevent the spread of . . . disease").

⁸³ See, e.g., *id.* at 1005 (noting that the individual states have the authority to require notification of diseases).

⁸⁴ See *id.* at 1006.

⁸⁵ See TOBEY, *supra* note 19, at 109.

⁸⁶ See Berkleman et al., *supra* note 56, at 735. In 1931, the Committee on Communicable Disease Control, as part of the White House Conference on Child Health and Protection, issued its recommendation that "there are certain diseases which should be reportable for all parts of the country," including diphtheria, epidemic influenza, measles, meningitis, polio-

myelitis, scarlet fever, note 71, at 96. Sus should be specially including tuberculosis [hereinafter STDs] b

⁸⁷ See, e.g., Berk, note 18, at 207-12; T

⁸⁸ See Gene W. M. in PRINCIPLES AND P

⁸⁹ See, e.g., Fox, &

⁹⁰ See *id.*

⁹¹ See ROSENAU, morbidity statistics

⁹² See Alberts v. tiality is one of the r

⁹³ Most states require professionals. Actual nature of the d to develop a trusting improve the therapeutic diagnosis and effectiveness as a general so the conflict between

⁹⁴ See Matthews

s of reportable
communicable
public health."⁷⁶
state health de-
ed.⁷⁷ Only later
which reporting
entieth century
rds by state or
ndard notifica-
nt's name, age,
al address to-
date of diagno-
ese cards were
tion, documen-
ss jurisdictions
toring tenuous
United States
apt to homoge-
d occupational
il 1925 did all
seases to the
e next several

categories of diseases

in standard morbid-
9, at 109 (same).
it 496-500.

state and territorial
are the information
rts. See *infra* text
rting requirements

reports is to allow
ority to require no-

on Communicable
and Protection, is-
e reportable for all
meningitis, polio-

decades, better organized public health efforts coupled with in-creasingly sophisticated surveillance techniques and elaborate pub-lication of morbidity information were instrumental in controlling epidemic diseases including poliomyelitis, malaria, and smallpox.⁸⁷

B. *The Tensions Between the Practice of Medicine and Public Health*

As mandatory reporting of infectious conditions became focal points of public health strategies in the early twentieth century a tension arose between physicians and public health authorities.⁸⁸ Public health officials saw their first duty to the population.⁸⁹ Re-ported dangerous conditions was essential to public health.⁹⁰ And since reporting practices relied on the efforts of practicing physi-cians, public health objectives required their voluntary coopera-tion.⁹¹ Physicians, on the other hand, saw their first duty to the in-dividual patient.⁹² Mandatory duties to report required physicians to produce the names and other information of their patients, breaching the traditional confidential relationship between doctors and patients.⁹³ Yet, failing to report cases of infectious disease tac-itly perpetuated the transmission of disease to "innocent victims."⁹⁴

myelitis, scarlet fever, smallpox, and typhoid fever." Communicable Disease Control, *supra* note 71, at 96. Suspected cases of cholera, plague, typhus fever, leprosy, and yellow fever should be specially reported. See *id.* The Committee recommended that other diseases, in-cluding tuberculosis, human anthrax and rabies, and various sexually transmitted diseases [hereinafter STDs] be reportable at the state or local level. See *id.*

⁸⁷ See, e.g., Berkleman et al., *supra* note 56, at 736; Centers for Disease Control, *supra* note 18, at 207-12; Thacker, *supra* note 19, at 5-6.

⁸⁸ See Gene W. Matthews & R. Elliot Churchill, *Public Health Surveillance and the Law*, in PRINCIPLES AND PRACTICE OF PUBLIC HEALTH SURVEILLANCE, *supra* note 19, at 193.

⁸⁹ See, e.g., Fox, *supra* note 27, at 11.

⁹⁰ See *id.*

⁹¹ See ROSENAU, *supra* note 60, at 1007-08 ("The original observers then, upon whom morbidity statistics depend chiefly for their completeness, are the practicing physicians.").

⁹² See *Alberts v. Devine*, 479 N.E.2d 113, 118-19 (Mass. 1985) (recognizing that confiden-tiality is one of the most important components of the doctor/patient relationship).

⁹³ Most states recognize a common law duty of confidentiality applying to certain health care professionals. Whether derived from the ethical obligations of physicians or the contrac-tual nature of the doctor/patient relationship, patient confidentiality is justified by the need to develop a trusting relationship to facilitate information exchange. See *id.* It is designed to improve the therapeutic process, by encouraging patient disclosure that assists in accurate diagnosis and effective treatment, and to strengthen the bond of the doctor/patient rela-tionship as a general social good. See generally Gostin et al., *supra* note 3, at 45-47 (discussing the conflict between individual rights and society's right to know).

⁹⁴ See Matthews & Churchill, *supra* note 88, at 193.

A doctor's duty of confidentiality, however, is more than an ethical promise to preserve a patient's health information pursuant to the Hippocratic Oath. Physicians may be liable for disclosing such information to third parties without the patient's consent.⁹⁵ Often described in tort law as a breach of confidentiality,⁹⁶ courts have also relied on various other theories of recovery, including invasion of privacy,⁹⁷ implied term of contract,⁹⁸ and breach of fiduciary relationship.⁹⁹ Breach of confidentiality claims have been upheld where a physician makes an unauthorized disclosure of information obtained in the course of a therapeutic relationship to various parties, including employers¹⁰⁰ or family members.¹⁰¹

Significant ethical and legal dilemmas arose from this conflict concerning the extent to which a patient's confidentiality should be

⁹⁵ See Lawrence O. Gostin et al., *Privacy and Security of Health Information in the Emerging Health Care System*, 5 HEALTH MATRIX 1, 15-16 (1995) (noting that significant gaps in legal abilities exist).

⁹⁶ See generally Alan B. Vickery, Note, *Breach of Confidence: An Emerging Tort*, 82 COLUM. L. REV. 1426 (1982) (analyzing the breach of confidence tort and its application in confidential relationships).

⁹⁷ The invasion of privacy theory effectuates the interest implicated in publicity cases, in which a person's reputation is at stake. The tort has significant doctrinal limitations in providing an adequate remedy for breach of confidentiality because it typically requires broad publication of the private matter, the public interest in knowing about public events or public figures may defeat the claim, and truth may be a defense. See RESTATEMENT (SECOND) OF TORTS § 652B-E (1977). In fact, there may be four distinct branches involved in an invasion of privacy theory: "Intrusion upon Seclusion," "Appropriation of Name or Likeness," "Publicity Given to Private Life," and "Publicity Placing Person in False Light." *Id.*

⁹⁸ Courts sometimes incorporate a duty of confidentiality into an implied service contract between the physician and patient. The expectation of confidentiality in the physician-patient relationship may be inferred from the ethical codes of medicine, the law of the state (for example, licensing requirements), or public policy favoring a strong therapeutic relationship, such as the maintenance of trust between doctor and patient. See *Hammonds v. Aetna Cas. & Sur. Co.*, 243 F. Supp. 793, 801 (N.D. Ohio 1965) (implying as a condition of the contract that "the doctor warrants that any confidential information gained through the relationship will not be released without the patient's permission"); *Doe v. Roe*, 400 N.Y.S.2d 668, 674 (Sup. Ct. 1977) (finding that the doctor-patient confidentiality had been breached when a psychiatrist reported the patient's thoughts, feelings, and fantasies).

⁹⁹ Some courts see the therapeutic relationship as imposing on the physician a fiduciary duty to the patient. A disclosure of private information without appropriate justification is deemed a breach of the fiduciary obligation. See *Ritter v. Rush-Presbyterian-St. Luke's Med. Ctr.*, 532 N.E.2d 327, 331 (Ill. App. Ct. 1988) (holding that the physician-patient privilege bars ex parte communications between a physician and his patient's legal adversary); *Alexander v. Knight*, 177 A.2d 142, 146 (Pa. Super. Ct. 1962) (same).

¹⁰⁰ See *Horne v. Patton*, 287 So. 2d 824, 830-31 (Ala. 1973) (holding that the physician's release of information to the patient's employer constituted an invasion of the patient's privacy); *Alberts v. Devine*, 479 N.E.2d 113, 118 (Mass. 1985) (same).

¹⁰¹ See *Humphers v. First Interstate Bank*, 696 P.2d 527, 530 (Or. 1985) (holding that the plaintiff had a cause of action for breach of a confidential relationship); *MacDonald v. Clinger*, 446 N.Y.S.2d 801, 806 (App. Div. 1982) (same).

sacrificed in t
senting their
partment,"¹⁰²
quiring them
"Among practi
has at times b
patient is priv
upon to impac
quirements a
tions.¹⁰⁵ Even
professionals f
statutes.¹⁰⁶ W
fession's view,
patient privac
medical profe
1960s.¹⁰⁷

With these
for maintainin
for the purpos
on doctors to
from governme
preserving pri
als alone who
his name repor

C. The In

With the pr
tious diseases

¹⁰² ROSENAU, *sup*

¹⁰³ See Fox, *supra*
tecting patient confi
front to their exclusi
by insurance and oth

¹⁰⁴ ROSENAU, *sup*
in jurisdictions requi

¹⁰⁵ See Fox, *supra*
public health official
disease reporting).

¹⁰⁶ See TOBEY, *su*
(Neb. 1920), which f
patient by reporting

¹⁰⁷ See Fox, *supra*

re than an ethi-
 ion pursuant to
 disclosing such
 onsent.⁹⁵ Often
 y,⁹⁶ courts have
 cluding invasion
 of fiduciary re-
 ve been upheld
 e of information
 to various par-

om this conflict
 tiality should be

th Information in the
 noting that significant

in *Emerging Tort*, 82
 and its application in

d in publicity cases, in
 inal limitations in pro-
 pically requires broad
 public events or public
 ATEMENT (SECOND) OF
 avolved in an invasion
 Name or Likeness,"
 e Light." *Id.*

plied service contract
 lity in the physician-
 e, the law of the state
 g therapeutic relation-
 e *Hammonds v. Aetna*
 a condition of the con-
 ned through the rela-
 v. *Roe*, 400 N.Y.S.2d
 ity had been breached
 sies).

physician a fiduciary
 opriate justification is
 terian-St. Luke's Med.
 ician-patient privilege
 legal adversary); Alex-

g that the physician's
 on of the patient's pri-

985) (holding that the
 nship); *MacDonald v.*

sacrificed in the performance of the duty to report. Perhaps re-
 senting their incorporation as "adjunct[s] of the [public] health de-
 partment,"¹⁰² doctors initially objected to state reporting laws re-
 quiring them effectively to breach their duty of confidentiality.¹⁰³
 "Among practicing physicians, at least in the United States, there
 has at times been the feeling that the knowledge of a disease in a
 patient is privileged information which they should not be called
 upon to impart."¹⁰⁴ Some doctors refused to honor reporting re-
 quirements altogether, subjecting themselves to criminal sanc-
 tions.¹⁰⁵ Eventually, legislative and judicial action relieved medical
 professionals from liability for failure to comply with the reporting
 statutes.¹⁰⁶ While release from liability did not, in the medical pro-
 fession's view, release them from their ethical obligations to protect
 patient privacy, compliance with reporting requirements by the
 medical profession gradually became commonplace by the late
 1960s.¹⁰⁷

With these developments came a marked shift of responsibility
 for maintaining the confidentiality of personal medical information
 for the purposes of public health. Individuals could no longer rely
 on doctors to preserve the confidentiality of their medical records
 from governmental reporting requirements. The responsibility for
 preserving private medical facts, instead, rested with the individu-
 als alone who might choose not to see a physician rather than have
 his name reported to government officials.

C. The Inception of the Modern Epidemic: National AIDS Reporting

With the protection of medical confidentiality concerning infec-
 tious diseases shifting from doctor to patient as a partial result of

¹⁰² ROSENAU, *supra* note 60, at 1009.

¹⁰³ See Fox, *supra* note 27, at 11, 13-14. Their objections were based on more than pro-
 tecting patient confidentiality. Physicians feared that public health programs were an af-
 front to their exclusive practice of medicine, constituting part of a "plot to regiment medicine
 by insurance and other means." *Id.* at 13.

¹⁰⁴ ROSENAU, *supra* note 60, at 1009 (stating that there is no legal basis for this position
 in jurisdictions requiring notification).

¹⁰⁵ See Fox, *supra* note 27, at 13-14 (discussing the tension between private doctors and
 public health officials); see also TOBEY, *supra* note 19, at 110 n.14 (citing cases which uphold
 disease reporting).

¹⁰⁶ See TOBEY, *supra* note 19, at 110 n.17 (citing *Simonsen v. Swenson*, 177 N.W. 831
 (Neb. 1920), which found that a physician does not violate his duty of confidentiality to his
 patient by reporting cases of communicable diseases).

¹⁰⁷ See Fox, *supra* note 27, at 14.

the reporting practices of the early twentieth century, the AIDS pandemic presented a new arena for this historic conflict between medical confidentiality and public health. Relieved of their duty of confidentiality by way of reporting statutes, doctors no longer could protect their patients' highly sensitive medical conditions. At-risk and infected individuals organized to protect their interests in preserving private medical information. Through well-organized campaigns, the privacy interests of infected individuals were vocalized.¹⁰⁸ Yet, curiously, a national system of AIDS reporting developed almost from the inception of the HIV/AIDS epidemic. Remarkably, while advocacy groups fiercely opposed HIV reporting, they exhibited little opposition to reporting CDC-defined AIDS.¹⁰⁹

The development of AIDS reporting can be understood only by examining its unique history.¹¹⁰ The AIDS epidemic emerged in the early 1980's.¹¹¹ After observing clusters of unusual pneumonia and rare cancers among gay men, the CDC determined that the syndrome's likely cause was a transmissible agent spread via the same routes as sexually transmitted diseases (STDs) like hepatitis B.¹¹² While this determination dispelled widespread fears of other forms of transmission,¹¹³ medical researchers were unable to determine early in the epidemic the causative agent of AIDS.

The CDC immediately recommended tracking similar cases of AIDS nationwide to further determine the parameters of the new disease and tailor prevention efforts to those at risk.¹¹⁴ In response to the CDC's recommendation, states uniformly implemented AIDS

reporting throughout the country, and this practice continues today.¹¹⁵ Persons diagnosed with AIDS are forwarded to state health departments for further relay of their characteristics.

AIDS reporting lacked a known, definite knowledge of the reporting generally inherent in private medical information, broadly accepted as a short period of time needed for health care thought to offset the risk.

It was not until the causative agent, the human immunodeficiency virus, Type I, was identified as the pathy-associated with the human immunodeficiency virus and Drug Abuse Administration until 1985, and

¹⁰⁸ See *infra* Part V.C (discussing the privacy aspect of the reporting debate).

¹⁰⁹ See Lawrence O. Gostin et al., *National HIV Case Reporting for the United States—A Defining Moment in the History of the Epidemic*, 337 NEW ENG. J. MED. 1162, 1163 (1997) (noting that AIDS surveillance has been in place since 1981).

¹¹⁰ See INSTITUTE OF MED., NAT'L ACADEMY OF SCIENCES, CONFRONTING AIDS: DIRECTIONS FOR PUBLIC HEALTH, HEALTH CARE, AND RESEARCH 63-65 (1986) (tracing the history of AIDS surveillance).

¹¹¹ See Gostin et al., *supra* note 109, at 1162 (noting that the causative agent of AIDS was discovered in 1983).

¹¹² See Donald P. Francis et al., *Epidemic Acquired Immune Deficiency Syndrome: Epidemiologic Evidence for a Transmissible Agent*, 71 J. NAT'L CANCER INST. 1, 1-4 (1983) (discussing the possible modes of transmission of AIDS); Henry Masur et al., *An Outbreak of Community-Acquired Pneumocystis Carinii Pneumonia: Initial Manifestation of Cellular Immune Dysfunction*, 305 NEW ENG. J. MED. 1431, 1431-38 (1981).

¹¹³ Cf. Lawrence K. Altman, *Case of HIV Transmission Is First To Be Linked to Kiss*, N.Y. TIMES, July 11, 1997, at A14 (noting that remote transmission of HIV has been documented to occur through kissing, noting that both the man and woman in this case of transmission suffered from gum disease making the likely cause of transmission by blood).

¹¹⁴ See Gostin et al., *supra* note 109, at 1163 (describing the process undertaken by medical professionals when a new AIDS case is discovered).

¹¹⁵ See Anna F. ... and Alternatives, ... reporting of AIDS is ... officially recognize

¹¹⁶ See Centers for Disease Control and Prevention, 1990s).

¹¹⁷ See Gostin, ... standards in the i

¹¹⁸ See BAYER, ... able given the cor ... at 1 (explaining t ... tice of reporting o

¹¹⁹ See American ... Feb. 5, 1998) <ht ... sons why AIDS re

¹²⁰ See Gostin ... for health and hu

¹²¹ See Franco ... Patient at Risk ... (1983) (noting th ... searchers); Rober ... (HTLV-III) from

¹²² See Carl H ... oping World, 9 A

tury, the AIDS
onflict between
of their duty of
no longer could
litions. At-risk
interests in pre-
organized cam-
als were vocal-
IDS reporting
IDS epidemic.
HIV reporting,
ned AIDS.¹⁰⁹
rstood only by
emerged in the
neumonia and
l that the syn-
d via the same
hepatitis B.¹¹²
of other forms
e to determine

milar cases of
ers of the new
¹¹⁴ In response
emented AIDS

ebate).
he United States—A
D. 1162, 1163 (1997)

ONTING AIDS: Di-
86) (tracing the his-
e agent of AIDS was

icy Syndrome: Epi-
INST. 1, 1-4 (1983)
t al., *An Outbreak of*
estation of Cellular

Linked to Kiss, N.Y.
as been documented
ase of transmission
od).
undertaken by medi-

reporting through the traditional named basis, a practice that continues today.¹¹⁵ The names and other pertinent information of persons diagnosed with CDC-defined AIDS are collected locally and forwarded to state public health authorities.¹¹⁶ This information is further relayed to the CDC (absent names or other identifying characteristics) for purposes of national surveillance.¹¹⁷

AIDS reporting was introduced at a time when the condition lacked a known source, much less the means to test for it. Without definite knowledge of the pathogen that causes AIDS, named AIDS reporting generated little public or political controversy despite the inherent privacy concerns.¹¹⁸ AIDS surveillance was, and still is, broadly accepted by persons living with HIV/AIDS.¹¹⁹ The relatively short period of patient survival once diagnosed, as well as the need for health and human services for infected individuals, were thought to offset the social risks of AIDS surveillance.¹²⁰

It was not until late 1983 that medical researchers identified the causative agent for AIDS, then called Human T-Cell Lymphotropic virus, Type III (HTLV-III) in the United States and Lymphadenopathy-associated virus (LAV) in France,¹²¹ and presently known as the human immuno-deficiency virus (HIV). The United States Food and Drug Administration did not license an antibody test for HIV until 1985, and then only to screen the nation's blood supply.¹²²

¹¹⁵ See Anna Forbes, *Naming Names: Mandatory Name-Based HIV Reporting: Impact and Alternatives*, 11 AIDS Pol'y & L. (BNA) 1, 1 (May, 1996 Bonus Report) ("Name-based reporting of AIDS diagnoses has been mandatory in the United States since the syndrome was officially recognized in 1982.").

¹¹⁶ See Centers for Disease Control, *supra* note 18, at 210 (discussing surveillance in the 1990s).

¹¹⁷ See Gostin et al., *supra* note 109, at 1163 (noting that case reports follow uniform standards in the interest of completeness, timeliness, and accuracy).

¹¹⁸ See BAYER, *supra* note 28, at 116-17 (stating that the lack of resistance was remarkable given the concerns about the privacy of individuals with AIDS); Forbes, *supra* note 115, at 1 (explaining that the public merely considered this policy a logical extension of the practice of reporting other STDs).

¹¹⁹ See American Civil Liberties Union, *HIV Surveillance and Name Reporting* (visited Feb. 5, 1998) <<http://www.aclu.org/issues/aids/namereport.html>> (discussing some of the reasons why AIDS reporting has raised little controversy).

¹²⁰ See Gostin et al., *supra* note 109, at 1162 (citing the short period of survival and need for health and human services as factors that balance the risks of reporting).

¹²¹ See Francoise Barre-Sinoussi et al., *Isolation of a T-lymphotropic Retrovirus from a Patient at Risk for Acquired Immune Deficiency Syndrome (AIDS)*, 220 SCI. 868, 868-71 (1983) (noting that the virus that appeared to cause AIDS had been isolated by French researchers); Robert C. Gallo et al., *Frequent Detection and Isolation of Cytopathic Retroviruses (HTLV-III) from Patients with AIDS and at Risk for AIDS*, 224 SCI. 500, 500-03 (1984).

¹²² See Carl H. Campbell, Jr. et al., *The Role of HIV Counseling and Testing in the Developing World*, 9 AIDS EDUC. & PREVENTION 92, 92 (1997) (noting that the antibody test has

Thus, name-based AIDS reporting was successfully implemented in response to this new epidemic. Reporting was accepted as a necessary practice to track those living with a disease whose cause was once unknown, but whose effect on health and well-being were overwhelming.

II. THE CHANGING FACE OF THE AIDS EPIDEMIC

The focus of surveillance on reporting an end-stage disease is understandable given the nature of the disease and the epidemic during the early years. CDC-defined AIDS was a diagnosable and consistent syndrome that could reliably be reported, and which provided a "gold standard" for disease reporting.¹²³ Moreover, there was no effective treatment and no biological method of curtailing effective treatment. At the same time, HIV infection posed substantial social risks of privacy invasion and discrimination.

What we have learned about the HIV/AIDS epidemic, through public health practices including named reporting and medical science, however, has changed drastically since its inception in 1981.¹²⁴ Developments in medical treatment may allow many HIV-infected individuals to remain asymptomatic for years, prolonging their life expectancy if not extending it indefinitely.¹²⁵ These same medical advancements may contribute to lowering the infectiousness of individuals who are HIV positive, making the virus more difficult to transmit.¹²⁶ Medical treatment of pregnant mothers infected with HIV may significantly reduce the rate of perinatal HIV transmission.¹²⁷ Although AIDS remains incurable, these medical

advances may
disease to a c
be controlled

The changi
fects on the
once believed
be active from
ment is critic
portunity to l
viduals are l
infection. As
related death
tory of the Ar
AIDS-related
HIV incidence
tional HIV m
speculative.
characteristic
of our nation's

After years
phisticated ac

been a major component of HIV prevention efforts since it first became available); Ronald O. Valdiserri, *HIV Counseling and Testing: Its Evolving Role in HIV Prevention*, 9 AIDS EDUC. & PREVENTION 2, 2-3 (1997) (discussing the emergence of testing as a standard prevention practice); Centers for Disease Control, *Provisional Public Health Service Interagency Recommendations for Screening Donated Blood and Plasma for Antibody to the Virus Causing Acquired Immunodeficiency Syndrome*, 34 MORBIDITY & MORTALITY WKLY. REP. 1, 1 (1985) (discussing the recommendations concerning the use of tests to screen blood and plasma).

¹²³ See Gostin et al., *supra* note 109, at 1163 (noting that AIDS has been a reportable condition since 1981).

¹²⁴ See *id.* at 1162 (discussing the marked increase in the level of sophistication of knowledge of the virus and its therapies).

¹²⁵ See *infra* notes 132-36 and accompanying text (discussing recent medical developments).

¹²⁶ See Gostin et al., *supra* note 109, at 1162.

¹²⁷ See Susan A. Fiscus et al., *Perinatal HIV Infection and the Effect of Zidovudine Therapy on Transmission in Rural and Urban Counties*, 275 JAMA 1483, 1486-87 (1996) (concluding that medical treatment is effective in reducing perinatal HIV transmission); Catherine Peckham & Diana Gibb, *Mother-to-Child Transmission of the Human Immunode-*

ficiency Virus, 333
and avoidance of br

¹²⁸ See David Br
at A4 (noting that s
Some AIDS rese
called "triple the
provided the tree
clearly won't hap
Id.

¹²⁹ See Pierce J.
Toward a Presump
L. REV. 471, 474 (1
cells).

¹³⁰ See A. Mark
that HIV-infected ir

¹³¹ See Mike Coo
Half of 1996 to Beti
(stating that expert
care).

lly implemented
cepted as a nec-
whose cause was
well-being were

DEMIC

ge disease is un-
d the epidemic
diagnosable and
, and which pro-
Moreover, there
iod of curtailing
tion posed sub-
nation.

idemic, through
and medical sci-
ts inception in
llow many HIV-
ears, prolonging
.125 These same
; the infectious-
the virus more
ant mothers in-
f perinatal HIV
e, these medical

available); Ronald O.
vention, 9 AIDS EDUC.
a standard prevention
vice Interagency Rec-
to the Virus Causing
VKLY. REP. 1, 1 (1985)
blood and plasma).
been a reportable con-

phistication of knowl-
cent medical develop-

ct of Zidovudine Ther-
1483, 1486-87 (1996)
al HIV transmission);
the Human Immunode-

advances may change our conception of HIV/AIDS from a terminal disease to a chronic, treatable condition, akin to diabetes, which can be controlled in individuals for decades.¹²⁸

The changing science and medicine, moreover, have profound effects on the symptomatology and epidemiology of HIV/AIDS. HIV, once believed to be a latent infection, has medically been shown to be active from the point of infection.¹²⁹ Early detection and treatment is critical to providing individuals infected with HIV the opportunity to live longer without visible symptoms.¹³⁰ At-risk individuals are being encouraged to be tested and treated for HIV infection. As treatment regimes are further administered, AIDS-related deaths have fallen for the first time in the fifteen-year history of the American epidemic.¹³¹ Yet a decrease in the number of AIDS-related deaths does not necessarily demonstrate that national HIV incidence is also decreasing. Without a reliable system of national HIV monitoring, lowered incidence of HIV infection remains speculative. These changes in the medical and epidemiological characteristics of the epidemic require a fundamental reevaluation of our nation's policy of monitoring the disease.

A. Developments in Medical Treatment

After years of frustration searching for a cure or vaccination, sophisticated advances in the treatment of HIV/AIDS have recently

iciency Virus, 333 NEW ENG. J. MED. 298, 301-02 (1995) (recommending medical treatment and avoidance of breast feeding to reduce perinatal HIV transmission).

¹²⁸ See David Brown, "Triple Therapy" Doesn't Destroy HIV, WASH. POST, Nov. 14, 1997, at A4 (noting that antiviral drug therapy only holds HIV at bay and does not eradicate it).

Some AIDS researchers had hoped that combinations of three antiviral drugs—often called "triple therapy"—might cure a person of HIV infection in as little as three years, provided the treatment was followed strictly. . . . While this scenario is still possible, it clearly won't happen on the schedule many had predicted—if it happens at all.

Id.

¹²⁹ See Pierce J. Reed & Laura Davis Smith, *HIV, Judicial Logic and Medical Science: Toward a Presumption of Noninfection in Child-Custody and Visitation Cases*, 31 NEW ENG. L. REV. 471, 474 (1997) (describing the effect of HIV infection of particular immune system cells).

¹³⁰ See A. Mark Isley, *Health Law Survey*, 71 DENV. U. L. REV. 981, 997 (1994) (noting that HIV-infected individuals can live and function with the disease).

¹³¹ See Mike Cooper, *AIDS Deaths Drop for 1st Time, U.S. Attributes 12% Decline in First Half of 1996 to Better Treatment, Slowing of Epidemic*, S.F. EXAMINER, Feb. 27, 1997, at A1 (stating that experts also attribute the decline to broadened access to effective treatment and care).

emerged.¹³² Though originally believed to be a latent infection, HIV pathogenesis is now known to produce high rates of viral replication and CD4+ cell death soon after transmission.¹³³ Individuals infected with HIV are thus immediately at risk of deterioration of their immune system, and of transmitting the infection.¹³⁴ Coincidentally with these findings, a newly-developed treatment regime of HIV reverse transcriptase inhibitors and protease inhibitors known as "triple therapy," or HAART, has been shown to reduce mortality and delay the symptomatic progression of the disease.¹³⁵ HIV-positive persons on HAART have demonstrated lower levels of circulating virus, thus reducing the risk of transmission to others.¹³⁶

¹³² Recently, the FDA announced its approval for the first time for an AIDS vaccine known as AIDSVAX, to undergo clinical trials using humans. See *AIDS Vaccine Approved for Human Trials*, WASH. POST, Jan. 12, 1998, at A11.

¹³³ See Alan S. Perelson et al., *HIV-1 Dynamics In Vivo: Virion Clearance Rate, Infected Cell Life-Span, and Viral Generation Time*, 271 SCI. 1582, 1582-86 (1996) (analyzing viral load data collected from five HIV infected individuals after the administration of a potent inhibitor of HIV-1 protease).

¹³⁴ See Scott M. Hammer et al., *A Trial Comparing Nucleoside Monotherapy with Combination Therapy in HIV-Infected Adults with CD4 Cell Counts from 200 to 500 Per Cubic Millimeter*, 335 NEW ENG. J. MED. 1081, 1081-88 (1996) (discussing how high rates of viral replication with rapid turnover of the virus and CD4 cells occurs from the onset of the infection).

¹³⁵ See Charles C.J. Carpenter et al., *Antiretroviral Therapy for HIV Infection in 1997: Updated Recommendations of the International AIDS Society—USA Panel*, 277 JAMA 1962, 1962-64 (1997) (concluding that new data has provided a stronger rationale for earlier initiation of more aggressive therapy); Ann C. Collier et al., *Treatment of Human Immunodeficiency Virus Infection with Zidovudine, Zalcitabine, and Zalcitabine*, 334 NEW ENG. J. MED. 1011, 1011-15 (1996) (concluding that studies are warranted to evaluate whether the three drug combination will reduce morbidity and mortality); Hammer, *supra* note 134, at 1081-88; Louis D. Saravolatz et al., *Zidovudine Alone or in Combination with Didanosine or Zalcitabine in HIV-Infected Patients with the Acquired Immunodeficiency Syndrome or Fewer than 200 CD4 Cells Per Cubic Millimeter*, 335 NEW ENG. J. MED. 1099, 1099-1106 (1996) (stating that combination therapy might be expected to delay disease progression and prolong survival with acceptable side effects).

¹³⁶ A possible drawback of Highly Active Antiretroviral Therapy [hereinafter HAART] is that it may tend to further the development of new, resistant strains of HIV, rendering existing treatment ineffective. With knowledge of the means by which HIV hooks itself to host cells, researchers have developed an "HIV-hunting virus" from a genetically redesigned cattle virus. The HIV-hunting virus unhooks HIV from its host cell and kills the virus in the process. A major advantage of this experimental therapy is that HIV would have to genetically redesign itself to ward off the modified cattle virus. See *News Notes*, 113 AIDS REFERENCE GUIDE 1, 1 (1997) (citing Matthias J. Schnell et al., *Construction of a Novel Virus that Targets HIV-1-Infected Cells and Controls HIV-1 Infection*, 90 CELL 849 (1997) (raising the possibility of an entirely new type of therapy for treating HIV and AIDS patients)).

Perinatal transmission from an HIV-infected child during birth or of pediatric HIV. There exists a high transmission among children at which transmission, delivery, and many cases. Many factors, characteristics of transmission, whether the

¹³⁷ See Pamela L. 1: Preliminary Analysis, 1925, 1925 (1994) (discussing the mortality of pediatric HIV).

¹³⁸ See *id.* (noting the ease of transmission).

¹³⁹ See Peckham.

¹⁴⁰ See Sheldon L. *Immunodeficiency* (1996) (indicating that the mother's transmission is a significant factor in clinical HIV disease and low birth weight).

¹⁴¹ The mother's transmission. See (CD4 counts indicating clinical HIV disease and low birth weight). ¹⁴² Studies have shown that delivery. See Boyer et al., *in utero or in birth*; Landesman et al., *the mother more than the duration of the infection*; also Boyer et al., *HIV-infected mothers and severe lacerations that cesarean section for HIV-positive women* (*The European Section Study*); *Reproductive Study*).

¹⁴³ Breast-feeding: 22%. See Angus et al., *Infective agents*.

B. Perinatal Transmission

Perinatal transmission refers to the vertical transmission of HIV from an HIV-positive pregnant mother to her unborn fetus or infant child during birth.¹³⁷ It is the principal means through which cases of pediatric HIV infection occur.¹³⁸ Without medical intervention there exists a fifteen to thirty-five percent chance of vertical transmission among HIV-positive pregnant women,¹³⁹ although the stage at which transmission of the virus occurs, whether during pregnancy, delivery, or postpartum through breastfeeding, is unclear in many cases.¹⁴⁰ Causes of vertical transmission of HIV involves many factors, including the mother's stage of infection and characteristics of the viral strain,¹⁴¹ incidents during delivery,¹⁴² and whether the mother breastfeeds.¹⁴³ Since all infants of HIV-

¹³⁷ See Pamela J. Boyer et al., *Factors Predictive of Maternal-Fetal Transmission of HIV-1: Preliminary Analysis of Zidovudine Given During Pregnancy and/or Delivery*, 271 JAMA 1925, 1925 (1994) (noting that maternal-fetal transmission of HIV-1 accounts for the majority of pediatric HIV infections).

¹³⁸ See *id.* (noting that transmission rates vary depending on different geographical areas).

¹³⁹ See Peckham & Gibb, *supra* note 127, at 298 (discussing perinatal transmission).

¹⁴⁰ See Sheldon H. Landesman et al., *Obstetrical Factors and the Transmission of Human Immunodeficiency Virus Type 1 from Mother to Child*, 334 NEW ENG. J. MED. 1617, 1617 (1996) (indicating that transmission occurs most frequently at or near delivery).

¹⁴¹ The mother's stage of HIV infection is likely the greatest determinant of the risk of transmission. See *id.* at 1621. If the mother has a high viral load count and a low CD4 count (CD4 counts indicate the stage of the HIV infection, lower counts suggest more advanced clinical HIV disease), the risk of transmission to the infant is greater. Maternal drug use and low birth weight also increase the risk of transmission. See *id.* at 1620.

¹⁴² Studies have suggested that a substantial proportion of infants acquire HIV at or near delivery. See Boyer et al., *supra* note 137, at 1925 (indicating that transmission usually occurs in utero or intrapartum because of an absence of HIV in cord and peripheral blood at birth); Landesman et al., *supra* note 140, at 1617. The presence of a ruptured membrane in the mother more than four hours before delivery almost doubles the risk of transmission regardless of the mode of delivery. See *id.* at 1621 (discussing the strong correlation between the duration of the ruptured membrane and the mother to infant transmission of HIV); see also Boyer et al., *supra* note 137, at 1929 (discussing events at birth that expose an infant to HIV-infected maternal blood, such as the use of fetal scalp electrodes, abruption, episiotomy, and severe laceration, all of which increase the probability of transmission). One study found that cesarean sections cut the rate of transmission in half, but posed a greater morbidity risk for HIV-positive women. See *Cesarean Section and Risk of Vertical Transmission of HIV-1 Infection (The European Collaborative Study)*, 343 LANCET 1464 (1994) [hereinafter *Cesarean Section Study*]; *Risk Factors for Mother-to-Child Transmission of HIV-1 (The European Collaborative Study)*, 339 LANCET 1007 (1992) [hereinafter *Risk Factors Study*].

¹⁴³ Breast-feeding has been found to increase the risk of vertical transmission from 7% to 22%. See Angus Nicoll et al., *Preventing Perinatal Transmission of HIV: The Effect of Breast-feeding*, 276 JAMA 1552, 1552 (1996) (letter to editor); see also Philippe Van de Perre et al., *Infective and Anti-Infective Properties of Breastmilk from HIV-1-Infected Women*, 341

infected mothers are antibody positive and testing infants for HIV infection through antibody testing,¹⁴⁴ or clinical diagnosis,¹⁴⁵ is difficult, it is impossible to know whether an infant is truly infected with HIV.

New medical treatment allows HIV-positive pregnant women to significantly reduce the risk of vertically transmitting the virus to their infants.¹⁴⁶ Prenatal treatment with Azidothymidine (AZT) has been found to reduce the risk of fetal transmission to eight percent.¹⁴⁷ The AIDS Clinical Trials Group Protocol 076 (ACTG 076) study suggests that AZT treatment prevents sixty-six percent of HIV infections in infants when administered to the mother early in the prenatal period and during labor, and to the infant after

birth.¹⁴⁸ Subsequently, it has been determined that a treatment administered to the mother during pregnancy can reduce the risk of their pregnant women to eight percent.¹⁴⁹ Moreover, the absence of invasive procedures, may further reduce the risk of infection. In addition, HIV treatment, by avoiding the risk of infection, however, requires the mother to be treated with HIV.

Although the use of HAART in clinical management of HIV strains of HIV/AIDS surveillance, new therapies

LANCET 914 (1993) (discussing the relationship between breastfeeding and milk properties that increase the risk of transmission).

¹⁴⁴ It is extremely difficult to diagnose infants because serologic tests may reflect passively acquired maternal antibodies that crossed the placental barrier resulting in false-positives. See Sheldon Landesman et al., *Clinical Utility of HIV-IgA Immunoblot Assay in the Early Diagnosis of Perinatal HIV Infection*, 266 JAMA 3443, 3443-44 (1991) (stating that detection of HIV-specific IgA antibodies in the infants serum should indicate the presence of an infection); Thomas C. Quinn et al., *Early Diagnosis of Perinatal HIV Infection by Detection of Viral-Specific IgA Antibodies*, 266 JAMA 3439, 3439 (1991) (stating that children born to mothers infected with HIV will be infected by passage either in utero, intrapartum, or postnatally). Polymerase chain reaction [hereinafter PCR] testing has a sensitivity of 30% to 60% during the first few weeks of life and 100% for children three to six months old. This degree of accuracy, however, requires rigorous quality control to avoid false-positives and is not yet adapted for clinical use. Another method of HIV diagnosis, the p24 antigen assay, predicts HIV infection early, but has poor sensitivity. See Landesman et al., *supra*, at 3445 (commenting on the P24 antigen assay).

¹⁴⁵ Doctors who suspect or know that a mother is infected with HIV may look for characteristic symptoms of HIV infection in the infant. See Jody W. Zylke, *Another Consequence of Uncontrolled Spread of HIV Among Adults: Vertical Transmission*, 265 JAMA 1798, 1798 (1991). However, HIV-infected infants typically are asymptomatic at birth. See Hermann Mendez & Jose Ernesto Jule, *Care of the Infants Born Exposed to Human Immunodeficiency Virus*, 17 OBSTETRICS & GYNECOLOGY CLINICS N. AM. 637, 638 (1990). Most become symptomatic within the first year and die before five years of age. In the first year of life, severe symptoms may develop, such as wasting, brain disorders, pneumonia, and recurrent bacterial infections. If the disease takes a more gradual course, lymphoid interstitial pneumonitis (inflammation of the lungs) and other recurrent bacterial infections occur. Of those children who reach age five, most develop a disease pattern similar to that seen in adults. See Marie-Jeanne Mayaux et al., *Neonatal Characteristics in Rapidly Progressive Perinatally Acquired HIV-1 Disease*, 275 JAMA 606, 606 (1996).

¹⁴⁶ See Fiscus et al., *supra* note 127, at 1483 (discussing measures of testing that help reduce the number of infants that are infected); Peckham & Gibb, *supra* note 127, at 298 (discussing advantages of testing and early detection of HIV infection).

¹⁴⁷ See Rhoda S. Sperling et al., *Maternal Viral Load, Zidovudine Treatment, and the Risk of Transmission of Human Immunodeficiency Virus Type 1 from Mother to Infant*, 335 NEW ENG. J. MED. 1621, 1622-23 (1996) (discussing treatments that reduce the risk of mother-infant transmission of the HIV virus).

¹⁴⁸ See *id.* The use of AZT during pregnancy and no previous AZT treatment during the first weeks of gestation following birth. See the protocol must be followed. It is suggested that early p. David Brown, *AZT at A6* (describing transmission even AZT therapy may prevent infections. In addition, nausea, headaches, occasional seizures, *Too Much, Too Little* effects of prolonged AZT treatment on the system. See Sama *AZT Treatment of 1*

¹⁴⁹ See David Brown, *WASH. POST*, Feb. 1998 (Thailand).

¹⁵⁰ See Peckham & Gibb, *supra* note 127, at 298 (discussing advantages of testing and early detection of HIV infection).

¹⁵¹ See *Cesarean*, *supra* note 127, at 298 (discussing advantages of testing and early detection of HIV infection).

¹⁵² See Centers for Disease Control and Prevention, *1996, 46 MORBIDITY AND MORTALITY REPORTING* (discussing HIV/AIDS diagnosis and treatment).

infants for HIV
infection,¹⁴⁵ is dif-
ficultly infected

ant women to
ing the virus to
line (AZT) has
to eight per-
cent (ACTG 076)
six percent of
mothers early in
infant after

and milk properties

may reflect pas-
sive resulting in false-
negative results in
immunoblot Assay in
(1991) (stating that
the presence of
infection by Detection
at children born to
maternal, or post-
natality of 30% to
months old. This
false-positives and is
p24 antigen assay,
al., *supra*, at 3445

may look for charac-
teristic Consequence of
JAMA 1798, 1798
th. See Hermann
Immunodeficiency
Most become symp-
tomatic year of life, severe
and recurrent bacte-
rial pneumoniae
Of those children
adults. See Marie-
annelle Acquired

stating that help re-
duce note 127, at 298

ment, and the Risk
to Infant, 335 NEW
the risk of mother-

birth.¹⁴⁸ Subsequent to the ACTG 076 study, the CDC has deter-
mined that a significantly less expensive and shorter course of AZT
treatment administered to pregnant women in the last four weeks
of their pregnancy may reduce perinatal transmission by up to fifty
percent.¹⁴⁹ Medical procedures at childbirth, including the avoid-
ance of invasive procedures or the election to undergo cesarean sec-
tion, may further decrease the risk of perinatal transmission.¹⁵⁰ In
addition, HIV-positive mothers can prevent risks of infant infection
by avoiding breastfeeding.¹⁵¹ Each of these preventive measures
however, requires advance knowledge that the mother is infected
with HIV.

C. Effects on Epidemiology

Although the long term benefits are unknown concerning the role
of HAART in reducing infectiousness, in delaying or preventing
clinical manifestations of disease, and in developing resistant
strains of HIV, these innovative therapies are already affecting
AIDS surveillance trends.¹⁵² Population-based data indicate that
new therapies are already significantly impeding the progression of

¹⁴⁸ See *id.* The narrow study included only women who had a CD4 count greater than 200
and no previous AZT treatment. See *id.* The protocol treated the women between 14 and 34
weeks of gestation through childbirth. See *id.* Infants were treated with AZT for six weeks
following birth. See *id.* The study failed to demonstrate whether the strict requirements of
the protocol must be present in order for the treatment to be effective, although it was sug-
gested that early prenatal intervention and the health of the mother are critical. See *id.*; cf.
David Brown, *AZT Effective in Pregnancy with Advanced AIDS*, WASH. POST, Mar. 27, 1997,
at A6 (describing a National Institute of Health study that found AZT prevents vertical
transmission even in advanced stages of HIV in the mother). There is also the concern that
AZT therapy may be detrimental because of the difficulty of administering lengthy treat-
ments. In addition, AZT as a powerful antiviral drug has significant side effects, including
nausea, headaches, muscle pains, anemia, neuropathy/myopathy, malaise, hyperactivity, and
occasional seizures. See Eileen M. McKenna, *The Mandatory Testing of Newborns for HIV:
Too Much, Too Little, Too Late*, 13 N.Y.L. SCH. J. HUM. RTS. 307, 323 (1997). Long term ef-
fects of prolonged AZT treatment include higher cancer risks and damage to the reproductive
system. See Samantha Catherine Halem, *At What Cost? An Argument Against Mandatory
AZT Treatment of HIV-Positive Pregnant Women*, 32 HARV. C.R.-C.L. L. REV. 491, 494 (1997).

¹⁴⁹ See David Brown, *Success with AZT Use in Pregnancy Alters Thinking on AIDS Policy*,
WASH. POST, Feb. 19, 1998, at A10 (discussing results of a study of 400 pregnant women in
Thailand).

¹⁵⁰ See Peckham & Gibb, *supra* note 127, at 299 (stating that avoiding procedures such as
cesarean sections reduces the risk of HIV transmission).

¹⁵¹ See *Cesarean Section Study*, *supra* note 142, at 1464 (indicating that breastfeeding can
contribute to HIV transmission); *Risk Factors Study*, *supra* note 142, at 1007 (same).

¹⁵² See Centers for Disease Control, *Update: Trends in AIDS Incidence—United States,
1996*, 46 MORBIDITY & MORTALITY WKLY. REP. 861, 861 (1997) (looking at the trend of de-
clining AIDS diagnoses).

HIV disease and altering the epidemiology of the epidemic.¹⁵³ In 1996, both AIDS deaths and the incidence of AIDS opportunistic illnesses declined for the first time in the history of the epidemic.¹⁵⁴ AIDS deaths decreased twenty-three percent from the prior year (to approximately 39,000 persons).¹⁵⁵ The decline was even greater for certain sub-populations, such as homosexual/bisexual men (thirty percent).¹⁵⁶ Furthermore, in 1996, the number of persons diagnosed with AIDS (approximately 56,500 adults) represented a six percent decline in AIDS incidence from 1995.¹⁵⁷

These positive developments in AIDS trends are even more compelling considering the relatively few HIV-positive individuals who may have yet undergone HAART. A CDC surveillance project of HIV-infected persons without AIDS-defining conditions receiving clinical care from 1996 through early 1997 found that only five percent of the 2932 subjects were prescribed an HIV protease inhibitor.¹⁵⁸ Revised treatment guidelines based on HIV burden and CD4+ lymphocyte values recommend that HIV-infected persons be treated long before they develop AIDS or become symptomatic for HIV disease.¹⁵⁹ As more HIV-infected persons are placed on therapy, the lowering effects on AIDS trends should become more compelling.

Thus, changes in the AIDS epidemic, including life prolonging treatment that reduces the infectiousness of persons living with HIV and effective treatment to potentially lower the number of cases of perinatal transmission, have profound effects on epidemiology.¹⁶⁰ While the number of AIDS cases is dropping, however, the prevalence of HIV infection largely remains unknown.

¹⁵³ See *id.* (stating that 1996 was the first calendar year in which AIDS incidence did not increase in America).

¹⁵⁴ See *id.*

¹⁵⁵ See *id.*

¹⁵⁶ See Gostin et al., *supra* note 109, at 1162; see also William A. Bradford, Jr., *The AIDS Epidemic and Health Care Reform*, 27 J. MARSHALL L. REV. 279, 282 (1994) (discussing the changing nature of communities at risk, mainly a declining homosexual/bisexual AIDS rate due to AIDS educational programs within the community).

¹⁵⁷ See Bradford, *supra* note 156, at 862 (stating that AIDS incidence in adults is on the decline).

¹⁵⁸ See Gostin et al., *supra* note 109, at 1162.

¹⁵⁹ See *id.*; see also Jody B. Gabel, *Liability for Knowing Transmission of HIV: The Evolution of a Duty To Disclose*, 21 FLA. ST. U. L. REV. 981, 984 n.14 (1994) (discussing how HIV attacks the CD4+ lymphocytes in the human body).

¹⁶⁰ See Gostin et al., *supra* note 109, at 1166 (indicating the positive results which flow from effective prevention).

Advancem
the HIV epid
dominantly
cumulation o
majority of s
collectively a
cidences of
prevalent, H
ence to objec

Since 1981
impact of th
AIDS survei
quiring labor
departments
defined AIDS
case reports
Personal info
diagnostic fa
status, and
eliminate d
AIDS cases

¹⁶¹ See general
the AIDS virus).

¹⁶² See Gostin
the number of HI

¹⁶³ Interesting
now agree with
health tool which
to carry out HIV
tion of named HI
would prefer that
fected individual.

¹⁶⁴ See Rodger
the Resurgence of
REV. 111, 130 n.
(emphasizing the

¹⁶⁵ See Tbl. A.

¹⁶⁶ See Gostin
dures are involve

¹⁶⁷ See Depart

III. HIV/AIDS REPORTING: CURRENT STATUS

Advancements in science have brought society face to face with the HIV epidemic. Still, public health authorities continue to predominantly monitor the disease nationally through statistical accumulation of information about individuals with AIDS.¹⁶¹ While a majority of states have implemented HIV reporting, these states collectively account for less than one-quarter of the alleged new incidences of infection.¹⁶² In states where HIV infection is most prevalent, HIV reporting is not allowed, largely in political deference to objections from at-risk groups.¹⁶³

A. AIDS Surveillance

Since 1981, national, state, and local monitoring of the scope and impact of the HIV/AIDS epidemic has been based primarily on AIDS surveillance.¹⁶⁴ Every state has a statute or regulation requiring laboratories and physicians to report to local or state health departments the names of persons newly diagnosed with CDC-defined AIDS.¹⁶⁵ To provide complete, timely, and accurate data, case reports follow uniform standards developed by the CDC.¹⁶⁶ Personal information collected for each case includes demographics, diagnostic facility, patient risk history, laboratory analysis, clinical status, and treatment/service referrals.¹⁶⁷ After cross checking to eliminate duplicates, state health departments relay confirmed AIDS cases to the CDC by way of electronic soundex code through

¹⁶¹ See generally Centers for Disease Control, *supra* note 152, at 851 (discussing trends in the AIDS virus).

¹⁶² See Gostin et al., *supra* note 109, at 1163 (discussing the effects of HIV reporting on the number of HIV infections in a majority of states).

¹⁶³ Interestingly, many of the same groups which objected to HIV reporting in the past now agree with public health authorities and others that HIV reporting is a viable public health tool which should be implemented. Such groups, however, do not agree on the means to carry out HIV reporting. As furthered analyzed, *see infra* notes 295-323, the implementation of named HIV reporting is still hotly contested by gay and civil liberties groups. They would prefer that HIV reporting utilize unique identifiers to protect the privacy of each infected individual.

¹⁶⁴ See Rodger Doughty, *The Confidentiality of HIV—Related Information: Responding to the Resurgence of Aggressive Public Health Interventions in the AIDS Epidemic*, 82 CAL. L. REV. 111, 130 n.75 (1994) (discussing surveillance); Gostin et al., *supra* note 109, at 1163 (emphasizing the importance of surveillance in AIDS research and analysis).

¹⁶⁵ See Tbl. A.

¹⁶⁶ See Gostin et al., *supra* note 109, at 1163 (stating that uniform standards and procedures are involved in case reporting).

¹⁶⁷ See Department of Health and Human Services, *supra* note 24.

the National Electronic Telecommunication System for Surveillance (NETSS), maintained as part of the National Notifiable Diseases Surveillance System (NNDSS).¹⁶⁸ All patient and provider identifiers are deleted from the data encrypted for aggregation at the national level.¹⁶⁹ Reporting of AIDS cases at the national level is thus accomplished without providing the names of infected individuals. National AIDS case counts are published by the CDC in its *Morbidity and Mortality Weekly Report*.¹⁷⁰ From 1981 through June 30, 1997, state and local health departments reported to the CDC a cumulative total of 612,078 AIDS cases.¹⁷¹

B. HIV Surveillance

HIV reporting is undertaken in much the same way as AIDS reporting: physicians and laboratories report HIV infection to local or state health officials who, in turn, forward aggregate data to the CDC.¹⁷² As summarized in Table A below, presently thirty-one states require confidential case surveillance of adults and adolescents who test positive for HIV infection.¹⁷³

State	Report of condition
AL	AIDS HIV
AK	AIDS
AZ	AIDS HIV
AR	AIDS HIV
CA	AIDS
CO	AIDS HIV
CT	AIDS HIV ¹⁷⁹
DE	AIDS
DC	AIDS
FL	AIDS HIV
GA	AIDS
HI	AIDS
ID	AIDS HIV
IL	AIDS
IN	AIDS HIV
IA	AIDS
KS	AIDS

¹⁶⁸ See Steven M. Teutsch, *Considerations in Planning a Surveillance System*, in PRINCIPLES AND PRACTICE OF PUBLIC HEALTH SURVEILLANCE, *supra* note 19, at 19 (describing how information is channeled using an electronic code).

¹⁶⁹ See Stroup et al., *supra* note 20, at 35 (stating that identifiers are not as useful at the national level as they are during the collection of data).

¹⁷⁰ See *id.* (stating that individual names are irrelevant in national reporting).

¹⁷¹ See Tbl. A and accompanying text.

¹⁷² See Centers for Disease Control, *HIV Infection: Reporting—United States*, 38 MORBIDITY & MORTALITY WKLY. REP. 496, 496-99 (1989) (describing the procedural aspects of AIDS reporting).

¹⁷³ These states include Alabama, Arizona, Arkansas, Colorado, Florida, Idaho, Indiana, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming. Connecticut, Texas, and Oregon have confidential name-based HIV reporting for pediatric cases only. Maryland and Texas have implemented adult HIV reporting through unique identifiers. See CENTERS FOR DISEASE CONTROL & PREVENTION, U.S. DEPT OF HEALTH & HUMAN SERVS., THE ROLE OF HIV SURVEILLANCE AS U.S. ENTERS NEW ERA IN THE EPIDEMIC 1 (1998).

¹⁷⁴ The Table is providing for, or a chart sources of jurisdictions which

¹⁷⁵ AIDS or HIV

¹⁷⁶ In actual n
CENTERS FOR DISE.
AIDS SURVEILLAN
REPORT].

¹⁷⁷ States and t
the highest numbe

¹⁷⁸ In actual nu
SURVEILLANCE REP
reported with HIV

¹⁷⁹ Connecticut

Table A
HIV/AIDS Reporting Among States and the
District of Columbia¹⁷⁴

State	Reporting of condition ¹⁷⁵	Statutory Source(s)	AIDS Cases ¹⁷⁶	Rank ¹⁷⁷	HIV Cases ¹⁷⁸
AL	AIDS HIV	ALA. CODE §§ 22-11A-13, 14 (1997)	4504	25	4335
AK	AIDS	ALASKA STAT. § 18.05.040.(a)(1) (Michie 1996)	385	46	—
AZ	AIDS HIV	ARIZ. REV. STAT. ANN. § 36-664(B) (West 1997)	5258	23	3574
AR	AIDS HIV	ARK. CODE ANN. § 20-15-904 (Michie 1991)	2270	33	1553
CA	AIDS	CAL. HEALTH & SAFETY CODE §§ 120805(a)(12), (13), 121065(c) (West 1997)	101,569	2	—
CO	AIDS HIV	COLO. REV. STAT. § 25-4-1402 (1997)	5962	21	5183
CT	AIDS HIV ¹⁷⁹	CONN. GEN. STAT. ANN. § 19a-583(a)(3) (West 1997)	9174	14	95
DE	AIDS	DEL. CODE ANN. tit. 16, § 702(a) (1995)	1922	35	—
DC	AIDS	D.C. CODE ANN. § 6-117(a)(2) (1981)	9946	11	—
FL	AIDS HIV	FLA. STAT. ANN. § 384.25(3) (West Supp. 1998)	62,200	3	N/A
GA	AIDS	GA. CODE ANN. § 38-723(h)(2) (1997)	17,985	8	—
HI	AIDS	HAW. REV. STAT. §§ 325-2, 325-104 (1994)	2028	34	—
ID	AIDS HIV	IDAHO CODE §§ 39-601, 39-602, 39-609 (1993)	394	45	282
IL	AIDS	410 ILL. COMP. STAT. ANN. 310/4, 325/4 (West 1993)	19,319	6	—
IN	AIDS HIV	IND. CODE ANN. § 16-41-2-3 (Michie 1993)	4779	24	2918
IA	AIDS	IOWA CODE ANN. § 141.8 (West 1998)	1028	40	—
KS	AIDS	KAN. STAT. ANN. § 65-6002 (Supp. 1997)	1919	36	—

¹⁷⁴ The Table summarizes those jurisdictions which have enacted statutory law explicitly providing for, or allowing, reporting of HIV or AIDS by state or local governments. It does not chart sources of administrative or common law which may authorize similar reporting in jurisdictions which have not otherwise enacted statutory law authorizing its implementation.

¹⁷⁵ AIDS or HIV.

¹⁷⁶ In actual numbers through June 1997, based on figures provided by the CDC. See CENTERS FOR DISEASE CONTROL & PREVENTION, U.S. DEP'T OF HEALTH & HUMAN SERVS., HIV/AIDS SURVEILLANCE REPORT 5 tbl.1 (midyear ed. 1997) [hereinafter CDC SURVEILLANCE REPORT].

¹⁷⁷ States and the District of Columbia are ranked from 1 to 51 (1 denoting the state with the highest number of AIDS cases reported through June 1997).

¹⁷⁸ In actual numbers through June 1997, based on figures provided by the CDC. See CDC SURVEILLANCE REPORT, *supra* note 176, at 26 tbl.22. HIV infection cases includes only persons reported with HIV infection who have not developed AIDS.

¹⁷⁹ Connecticut has confidential HIV reporting for pediatric cases only. See *id.*

r Surveillance
able Diseases
vider identifi-
ion at the na-
l level is thus
d individuals.
in its *Morbidity*
ugh June 30,
to the CDC a

y as AIDS re-
tion to local or
e data to the
tly thirty-one
s and adoles-

illance System, in
9, at 19 (describing

not as useful at the
orting).

d States, 38 MOR-
cedural aspects of

da, Idaho, Indiana,
t, New Jersey, New
na, South Dakota,
onnecticut, Texas,
es only. Maryland
fers. See CENTERS
SERVS., THE ROLE OF

State	Reporting of condition	Statutory Source(s)	AIDS Cases	Rank	HIV Cases
KY	AIDS	KY. REV. STAT. ANN. § 214.181(5)(c)(5) (Michie 1995)	2401	32	—
LA	AIDS HIV	LA. REV. STAT. ANN. § 1300.14(B)(6) (West 1992)	9660	13	5221
ME	AIDS	ME. REV. STAT. ANN. tit. 22, § 822 (West 1992)	783	43	—
MD	AIDS	MD. CODE ANN., HEALTH-GEN. I §§ 18-201, 18-205 (1994 & Supp. 1997)	16,223	9	—
MA	AIDS	MASS. ANN. LAWS ch. 111, §§ 6, 111 (Law. Co-op. 1995)	12,523	10	—
MI	AIDS HIV	MICH. STAT. ANN. §§ 14.15(5114)-(5114a) (Law. Co-op. 1995)	8770	16	3902
MN	AIDS HIV	MINN. STAT. ANN. § 144.05(c) (West Supp. 1998)	3095	28	2210
MS	AIDS HIV	MISS. CODE ANN. § 41-23-1 (Supp. 1997)	3050	29	3529
MO	AIDS HIV	MO. ANN. STAT. §§ 191.653(3), 191.656(2)(1)(a) (West 1996)	7487	19	3668
MT	AIDS	MONT. CODE ANN. § 50-16-530(2) (1997)	249	48	—
NE	AIDS HIV	NEB. REV. STAT. ANN. §§ 71-502.04, 71-503 (Michie 1996)	843	41	320
NV	AIDS HIV	NEV. REV. STAT. ANN. § 441A.170 (Michie 1996)	3300	27	2439
NH	AIDS	N.H. REV. STAT. ANN. §§ 141-C:7, 141-F:7(I)(b) (1996)	729	44	—
NJ	AIDS HIV	N.J. STAT. ANN. § 26:5C-6 (West 1996)	34,871	5	12,006
NM	AIDS HIV	N.M. STAT. ANN. §§ 24-1-7, 24-2B-6(D) (Michie 1997)	1522	38	—
NY	AIDS	N.Y. PUB. HEALTH LAW § 2782(1)(g) (McKinney 1993)	113,549	1	—
NC	AIDS HIV	N.C. GEN. STAT. § 130A-144 (1997)	7742	18	7435
ND	AIDS HIV	N.D. CENT. CODE § 23.07-02.1 (Supp. 1997)	85	51	63
OH	AIDS HIV	OHIO REV. CODE ANN. § 3701.241(A)(1) (Anderson 1997)	9109	15	3676
OK	AIDS HIV	OKLA. STAT. ANN. tit. 63, § 1-503 (West 1997)	2886	31	1831
OR	AIDS HIV ¹⁸⁰	OR. REV. STAT. § 433.045(3) (1997)	4021	26	3
PA	AIDS	35 PA. CONS. STAT. ANN. §§ 521.4, 7607(a)(8)(9) (West 1993)	18,388	7	—
RI	AIDS	R.I. GEN. LAWS § 23-6-17 (1996)	1668	37	—
SC	AIDS HIV	S.C. CODE ANN. §§ 44-29-70, 44-29-80 (Law. Co-op. Supp. 1997)	6661	20	6103
SD	AIDS HIV	S.D. CODIFIED LAWS § 34-23-2 (Michie 1994)	122	50	173

¹⁸⁰ Oregon has confidential HIV reporting for children less than six years old. *See id.*

State	Report of condi
TN	AIDS HIV
TX	AIDS HIV ¹⁸¹
UT	AIDS HIV
VT	AIDS
VA	AIDS HIV
WA	AIDS
WV	AIDS HIV
WI	AIDS HIV
WY	AIDS HIV

¹⁸¹ Texas has co

¹⁸² Cumulative f
possession, and ass

¹⁸³ Cumulative fi
states with HIV re

Rank	HIV Cases
32	—
13	5221
43	—
9	—
10	—
16	3902
28	2210
29	3529
19	3668
48	—
41	320
27	2439
44	—
5	12,006
38	—
1	—
18	7435
51	63
15	3676
31	1831
26	3
7	—
37	—
20	6103
50	173

State	Reporting of condition	Statutory Source(s)	AIDS Cases	Rank	HIV Cases
TN	AIDS HIV	TENN. CODE ANN. §§ 68-10-101 (1996)	5947	22	4221
TX	AIDS HIV ¹⁸¹	TEX. HEALTH & SAFETY CODE ANN. §§ 81.046, 81.047, 81.103 (West 1992)	42,185	4	223
UT	AIDS HIV	UTAH CODE ANN. § 26-6-3.5(1)(a) (Supp. 1997)	1449	39	789
VT	AIDS	VT. STAT. ANN. tit. 18, § 1004 (1982)	316	47	—
VA	AIDS HIV	VA. CODE ANN. § 32.1-36.1(3), (12) (Michie 1997)	9699	12	6664
WA	AIDS	WASH. REV. CODE ANN. § 70.24.105(c) (West Supp. 1998)	7930	17	—
WV	AIDS HIV	W. VA. CODE § 16-3C-3(a)(6) (1995)	801	42	427
WI	AIDS HIV	WIS. STAT. ANN. § 252.15(5)(a)(6) (West 1991)	2916	30	2084
WY	AIDS HIV	WYO. STAT. ANN. § 35-4-132(a) (Michie 1997)	153	49	59
CUMULATIVE TOTALS			591,775 ¹⁸²	—	84,986 ¹⁸³

¹⁸¹ Texas has confidential HIV reporting for pediatric cases only. *See id.*

¹⁸² Cumulative figure does not include 20,303 cases of AIDS reported in U.S. dependencies, possession, and associated nations. *See id.* at 5.

¹⁸³ Cumulative figure does not include 1986 cases of HIV infection of persons reported from states with HIV reporting who were residents of other states. *See id.* at 26.

Three states, Connecticut, Texas, and Oregon, conduct HIV surveillance for pediatric cases only.¹⁸⁴ Although a majority of states require name-based HIV reporting for adults and adolescents, they collectively accounted for less than one-third of the AIDS cases reported to the CDC through 1997.¹⁸⁵ Of the ten states with the highest numbers of reported AIDS cases through June 1997, only New Jersey, Florida, and Louisiana conduct HIV case surveillance for all populations.¹⁸⁶ States like New York and California, which had the two highest rates among states of reported AIDS cases last year, do not require HIV reporting at all.¹⁸⁷ As a result AIDS reporting remains a primary means of national surveillance.

IV. PUBLIC HEALTH JUSTIFICATIONS FOR A NATIONAL SYSTEM OF HIV REPORTING

We propose that there are compelling justifications for a national system of HIV reporting on a named basis,¹⁸⁸ provided the legal and ethical concerns of infected individuals and others at risk are adequately addressed through privacy and anti-discrimination protections. Principal among these compelling reasons for HIV reporting may be the simple recognition that the epidemic American society now faces is no longer a plague of unstoppable, deadly disease among predominantly gay persons, but a potentially controllable chronic condition with increasing effects on heterosexuals, women, and children.

¹⁸⁴ Connecticut and Texas require reporting for pediatric cases of children less than 13 years old. Oregon requires reporting for pediatric cases of children less than 6 years of age. See *id.* at 29 (discussing the various restrictions on reporting and the relationship of reporting and age).

¹⁸⁵ See *id.* at 1 (stating that very few reports to the CDC are accompanied by names of the HIV-infected person).

¹⁸⁶ See *id.*

¹⁸⁷ See Tbl. A; see also Robert Steinbrook, *Battling HIV on Many Fronts*, 337 NEW ENG. J. MED. 779, 779 (1997) (stating that HIV is reportable in about three-fifths of the states); Lynda Richardson, *U.S. Urges Identification of Patients with H.I.V.*, N.Y. TIMES, Oct. 21, 1997, at B5 (indicating that many have proposed mandatory HIV/AIDS reporting).

¹⁸⁸ See, e.g., CENTERS FOR DISEASE CONTROL ADVISORY COMM. ON THE PREVENTION OF HIV INFECTION, EXTERNAL REVIEW OF CDC'S HIV PREVENTION STRATEGIES (1994) (on file with author); CENTERS FOR DISEASE CONTROL, STRATEGIC PLAN FOR PREVENTING HUMAN IMMUNODEFICIENCY VIRUS (HIV) INFECTION 1 (1992) (on file with author); COUNCIL OF STATE & TERRITORIAL EPIDEMIOLOGISTS, POSITION STATEMENT, CONFIDENTIAL REPORTING OF HIV INFECTION (1997) (on file with author); John W. Ward et al., *Annotation: What Will Be the Role of HIV Infection Reporting?*, 84 AM. J. PUB. HEALTH 1888, 1888-89 (1994) (proposing a named-based system of reporting in order to avoid duplicate reporting and to allow for follow-up checks).

HIV reporting, in-d
ropevalence
It is importa
stage of deve
practice gro
infectious di
port among
groups.¹⁹¹ T
demiologists
public healt
past year for
ommendatio
responsible f
tions are rep

¹⁸⁹ See James
Approach for Mor
use of sero-preval
Disease in Person
JAMA 1798, 1799
ricia Sweeney et
menting AIDS Su
ployed by other cc

¹⁹⁰ See Forbes,
STDs).

¹⁹¹ See Americ
need for HIV sur
ACTION COUNCIL,
IDENTIFIER AND O
need for HIV sur
ASSOCIATION OF
SURVEILLANCE 1
tion of federal f
TERRITORIAL EPI
PUBLIC HEALTH
name-based HIV
NASTAD STATEM
provided strict cor
POSITION PAPER
surveillance syste
AIDS FOUND., E
STATEMENT OF TH
proved HIV data t

¹⁹² See Centers
in Atlanta on May
See *id.*

¹⁹³ See Teutsch

duct HIV sur-
villancy of states
escents, they
IDS cases re-
with the high-
97, only New
illiance for all
which had the
last year, do
reporting re-

SYSTEM OF

for a national
the legal and
risk are ade-
uation protec-
HIV reporting
erican society
eadly disease
controllable
uals, women,

ren less than 13
an 6 years of age.
ionship of report-

d by names of the

337 NEW. ENG. J.
hs of the states);
TIMES, Oct. 21,
rtng).

VENTION OF HIV
94) (on file with
VENTING HUMAN
OUNCIL OF STATE
PORTING OF HIV
What Will Be the
994) (proposing a
allow for follow-

HIV reporting can be an important component of a comprehensive HIV/AIDS surveillance system that also includes AIDS reporting, in-depth interviews, medical record reviews, unlinked seroprevalence surveys, and sampling representative populations.¹⁸⁹ It is important to observe that reporting of disease at the earliest stage of development is not unusual, but is standard public health practice grounded in historical epidemiology for all other significant infectious diseases.¹⁹⁰ National HIV reporting has widespread support among American public health authorities and interest groups.¹⁹¹ The CDC and the Council of State and Territorial Epidemiologists (CSTE) have convened several national meetings of public health representatives, AIDS activists, and others in the past year for the purpose of developing the parameters of their recommendations for national HIV reporting.¹⁹² The CSTE, which is responsible for recommending to the CDC which infectious conditions are reportable,¹⁹³ has advocated HIV reporting for years.¹⁹⁴ As

¹⁸⁹ See James W. Buehler et al., *The Supplement to HIV/AIDS Surveillance Project: An Approach for Monitoring HIV Risk Behaviors*, 111 PUB. HEALTH REP. 133, 133 (1996) (noting use of sero-prevalence surveys by health departments); Karen M. Farizo et al., *Spectrum of Disease in Persons with Human Immunodeficiency Virus Infection in the United States*, 267 JAMA 1798, 1799 (1992) (noting that data collection was facilitated by medical records); Patricia Sweeney et al., *Monitoring Current HIV Transmission To Promote Prevention: Supplementing AIDS Surveillance*, 9 J. AIDS 645, 645 (1995) (discussing surveillance methods employed by other countries).

¹⁹⁰ See Forbes, *supra* note 115, at 1 (stating that such a policy exists for syphilis and other STDs).

¹⁹¹ See American Civil Liberties Union, *supra* note 119, at 3 (acknowledging public health need for HIV surveillance despite strong opposition to named HIV reporting); see also AIDS ACTION COUNCIL, AIDS ACTION RESOLUTION IN SUPPORT OF HIV REPORTING BY UNIQUE IDENTIFIER AND OTHER NON NAME-BASED SURVEILLANCE SYSTEMS 1 (1997) (acknowledging a need for HIV surveillance through non name-based methods and with full federal funding); ASSOCIATION OF STATE & TERRITORIAL HEALTH OFFICERS, POLICY STATEMENT ID-4 HIV SURVEILLANCE 1 (1997) (recommending named HIV reporting by all states but not as a condition of federal funding for AIDS treatment and prevention); COMMITTEE OF STATE & TERRITORIAL EPIDEMIOLOGISTS, NATIONAL HIV SURVEILLANCE: ADDITION TO THE NATIONAL PUBLIC HEALTH SURVEILLANCE SYSTEM 1 (1997) (recommending state implementation of name-based HIV surveillance); NATIONAL ALLIANCE OF STATE & TERRITORIAL AIDS DIRS., NASTAD STATEMENT ON HIV SURVEILLANCE 1 (1997) (recommending named HIV reporting provided strict confidentiality is maintained); NATIONAL ASS'N OF PEOPLE WITH AIDS, POLICY POSITION PAPER ON MONITORING OF THE HIV EPIDEMIC 1 (1997) (supporting expansion of surveillance systems to include HIV reporting, although not named-based); SAN FRANCISCO AIDS FOUND., EXECUTIVE SUMMARY OF THE HIV SURVEILLANCE AND REPORTING POLICY STATEMENT OF THE SAN FRANCISCO AIDS FOUNDATION 1 (1997) (acknowledging need for improved HIV data through means other than mandatory reporting).

¹⁹² See Centers for Disease Control, *supra* note 152, at 861. The CDC and CSTE convened in Atlanta on May 21-22, 1997 for the Consultation on the Future of HIV/AIDS Surveillance. See *id.*

¹⁹³ See Teutsch, *supra* note 168, at 27.

recently as September 1997, the CDC affirmed that "[a]ll states and territories should conduct HIV case surveillance as an extension of their AIDS Surveillance programs."¹⁹⁵

A national system of confidential HIV case reporting would improve epidemiological understanding of the epidemic and assist in the targeting of effective prevention and public health services. It would allow authorities to link nationally at-risk and infected individuals with personal and public health and social services, including partner notification services. National HIV reporting would produce fairer decisions about resource allocation of limited funds to combat the epidemic. Authorities would possess accurate data enabling them to distribute funds in accordance with HIV incidence trends. Finally, national HIV reporting could provide data to change eligibility criteria for government benefit programs such as Medicaid. By using HIV, rather than AIDS, as an eligibility standard, benefit programs would be fairer and more effective. As explained in the following sections, we continue to have reservations about named-based HIV reporting. The benefits of HIV reporting are not always clear, and the potential for violation of individual rights remain. Yet, if implemented with adequate safeguards of privacy, security, and anti-discrimination, the public health benefits are far more likely to outweigh potential social risks.

A. Monitoring the AIDS Epidemic

There remain many unanswered questions concerning the HIV/AIDS epidemic under the existing national AIDS surveillance system. How many people in the United States are infected with HIV? How many of these infections are newly acquired and diagnosed? How were these newly diagnosed infections contracted? Are persons living with HIV receiving appropriate medical and social services? How effective is treatment and what strains of HIV are becoming resistant to treatment? Which communities have the highest rate of new infections? Answers to these questions bene-

¹⁹⁴ The CSTE's recommendation in favor of HIV reporting by each state extends back to May 1989. See COUNCIL OF STATE & TERRITORIAL EPIDEMIOLOGISTS, CSTE POSITION STATEMENT NO. 2, HIV INFECTION REPORTING (1989) ("CSTE recommends that each state public health agency consider instituting required reporting of HIV infection and encourages such reporting.").

¹⁹⁵ Centers for Disease Control, *supra* note 152, at 861 (noting that the CDC is offering assistance to all states in the form of surveillance policy and technical guidance to facilitate this effort).

fitting public alike require monitor what instead of an existing AIDS

A national would notably by yielding data monitor the transmitted behaviors and recent HIV incidence of the epidemic rely on pictures. Third, monitoring of the new characteristic surveillance severity (e.g., HIV opportunistic infections) characterize the access to, and

B.

An improved foundation would evaluate effectiveness facilitate these decisions such as rely on scarce resources to geographic needs, health mission. Research are effective in

¹⁹⁶ Modes of transmission, equipment, or accident

¹⁹⁷ See Centers for Disease Control, retroviral therapy

¹⁹⁸ See Gostin et al., system would provide

[a]ll states and an extension of

ting would im-
c and assist in
th services. It
d infected indi-
al services, in-
eporting would
limited finds to
urate data ena-
HIV incidence
rovide data to
ograms such as
eligibility stan-
fective. As ex-
ve reservations
HIV reporting
n of individual
safeguards of
ic health bene-
sks.

oncerning the
DS surveillance
e infected with
ired and diag-
ontracted? Are
ical and social
ins of HIV are
ities have the
uestions bene-

tate extends back to
rs, CSTE POSITION
nds that each state
tion and encourages

the CDC is offering
uidance to facilitate

fitting public health authorities and infected at-risk individuals alike require effective surveillance techniques. Yet, our ability to monitor what is increasingly becoming an epidemic of viral disease instead of an end-stage terminal illness is extremely limited by the existing AIDS surveillance system.

A national HIV surveillance system, including HIV reporting, would notably improve epidemiological assessments of the epidemic by yielding data about its relevant points. First, the system would monitor the methods by which HIV infection is acquired and transmitted by measuring the precursors to infection such as risk behaviors and modes of transmission.¹⁹⁶ Second, data collection on recent HIV infections would offer a window into the emerging trend of the epidemic. No longer would public health authorities have to rely on pictures of an end-stage epidemic that developed years ago. Third, monitoring HIV related deaths would improve understanding of the number of persons living with HIV infection and the characteristics of those who fail treatment. Finally, a national HIV surveillance system would collect laboratory markers of disease severity (e.g., HIV RNA, CD4+ values) and monitor preventable opportunistic illnesses. This would enable health authorities to characterize the natural history of HIV disease and to evaluate the access to, and efficacy of, medical treatment.

B. Targeting Prevention and Other Services

An improved monitoring system in which HIV reporting is the foundation would also help public health authorities target and evaluate effective prevention services.¹⁹⁷ HIV reporting would facilitate these efforts by pinpointing areas of need. Prevention services such as population-based testing, counseling, and education, rely on scarce governmental resources.¹⁹⁸ By directing these resources to geographic areas and sub-populations with the greatest needs, health authorities could most efficiently reduce HIV transmission. Research suggests that targeted HIV prevention services are effective in both averting infections in high risk populations and

¹⁹⁶ Modes of transmission include sexual, perinatal, multi-person use of drug injection equipment, or accidental needle sticks. See Gostin et al., *supra* note 109, at 1163.

¹⁹⁷ See Centers for Disease Control, *supra* note 152, at 861 (stating that advances in retroviral therapy have increased further the need for more effective targeting efforts).

¹⁹⁸ See Gostin et al., *supra* note 109, at 1163 (explaining that an improved surveillance system would provide for better allocation of scarce resources).

reducing costs.¹⁹⁹ Enhanced surveillance also assists in community planning for HIV prevention, implementing public health strategies, and evaluating their efficacy. For example, a recent CDC analysis found that states conducting HIV surveillance in 1993 were able to identify forty-nine percent of children born to infected mothers, compared with five percent in states that reported AIDS alone.²⁰⁰ These types of data could enable states to develop more effective prevention strategies to reduce perinatal transmission and provide services for HIV-infected mothers and children.

C. Linking HIV-Infected Persons with Treatment Opportunities, Educational Services, and Partner Notification Support Services

HIV surveillance cannot only assist authorities in targeting prevention services to communities on the macro-level, it can also help link individuals to services on a micro-level. Where HIV infection is reportable, public health authorities can assume timely referrals for health and social services including counseling, education, treatment, and voluntary partner notification support services. Access to these services can help prevent the spread of infection. Studies suggest that client-centered counseling and health education reduce risks for HIV transmission.²⁰¹ Persons with HIV/AIDS who receive early treatment increase the likelihood of living longer and higher quality lives.²⁰² As the CDC reports, "ensuring timely access to

HIV-care ser
cause in man
diagnosed."²⁰
and treatmer
HIV-infected

Improved
with HIV int
such as part
of disease.²⁰⁶
ices. Others
those related
national HIV
individuals r
lic health au
available. Th
previously ar
tice has not
the transmis
HIV.²⁰⁸ Tha
support servi
may, howeve
public health

¹⁹⁹ See James G. Kahn, *The Cost-Effectiveness of HIV Prevention Targeting: How Much More Bang for the Buck?*, 86 AM. J. PUB. HEALTH 1709, 1711 (1996) (noting that intervention in high risk groups also leads to benefits to members of low risk groups).

²⁰⁰ See Pascale M. Wortley et al., *Using HIV/AIDS Surveillance To Monitor Public Health Efforts To Reduce Perinatal Transmission of HIV*, 11 J. AIDS 205, 205-06 (1996) (emphasizing that HIV surveillance is an integral part of the efforts to reduce perinatal transmission).

²⁰¹ See M. Kamb et al., *Does HIV/STD Counseling Work? Results From a Randomized Controlled Trial (Project Respect)*, Address Before the Fourth Conference on Retroviruses and Opportunistic Infections (Jan. 22-26, 1997); CENTERS FOR DISEASE CONTROL & PREVENTION, U.S. DEP'T OF HEALTH & HUMAN SERVS., HIV COUNSELING, TESTING, AND REFERRAL STANDARDS AND GUIDELINES 3 (1994).

²⁰² See Schlomo Staszewski et al., *Reductions in HIV-1 Disease Progression for Zidovudine/Lamivudine Relative to Control Treatments: A Meta-Analysis of Controlled Trials*, 11 AIDS 477, 481 (1997) (discussing the results of four trials in which patients treated with ZDV/3TC showed a reduction in the progression of the virus); Department of Health and Human Services, *Report of the NIH Panel To Define Principles of Therapy of HIV Infection and Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults* (visited Feb. 5, 1998) <<http://www.hivpositive.com/f-DrugAdvisories/NIHguidlinesJune/1GuidelineMenu.html>>; Department of Health and Human Services, *Guidelines for the Use of Antiretroviral Agents in HIV Infected Adults and Adolescents* (visited Feb. 5, 1998) <<http://www.hivpositive.com/f-DrugAdvisories/NIHguidlinesJune/2-ReportMenu.html>>.

²⁰³ Centers for counseling and tes
ble to HIV-infected

²⁰⁴ See ASSOCI
HEALTH PRACTICE
notification is ess
treatment, which
Ronald Bayer & K
tion, 82 AM. J. PU
is critical as AIDS
ness levels are mu

²⁰⁵ See Forbes,

²⁰⁶ See Gostin &

²⁰⁷ See Gostin &
will increase acces
riers).

²⁰⁸ See Gostin &

in community health strategies. A recent CDC release in 1993 points to infected persons who reported AIDS and develop more effective transmission and prevention.

Opportunities, Support Services

Targeting prevention can also help HIV infection is by referrals for vaccination, treatment services. Access to care. Studies indicate that vaccination reduce AIDS who receive earlier and higher quality access to

getting: How Much of that intervention

Monitor Public Health 105, 205-06 (1996) to reduce perinatal

from a Randomized trial on Retroviruses: CONTROL & PRE-TESTING, AND RE-

gression for Zidovudine-controlled Trials, 11 patients treated with treatment of Health and Society of HIV Infection (visited Feb. 5, 1997) Guideline Menu. Use of Antiretroviral Therapy /www.hivpositive-

HIV-care services for HIV-infected persons remains important because in many persons HIV infection is not diagnosed until AIDS is diagnosed.²⁰³ Furthermore, case reporting facilitates notification and treatment referral of the sexual and needle-sharing partners of HIV-infected persons.²⁰⁴

Improved surveillance, of course, will not ensure that persons with HIV infection receive services,²⁰⁵ nor that services rendered, such as partner notification, are effective in controlling the spread of disease.²⁰⁶ Some may not choose to participate in various services. Others face significant barriers to receiving them, including those related to cost, geographic accessibility, and culture.²⁰⁷ While national HIV reporting will not guarantee that at-risk and infected individuals receive such services, it can facilitate the ability of public health authorities to refer individuals to those services that are available. The efficacy of such services is another matter. We have previously argued that partner notification as a public health practice has not conclusively been shown to be effective in controlling the transmission of some sexually-transmitted diseases, including HIV.²⁰⁸ That HIV surveillance may facilitate partner notification support services thus may not effectively control the epidemic. It may, however, allow for the further implementation and study of public health practices which are more effective.

²⁰³ Centers for Disease Control, *supra* note 152, at 861 (explaining that improved HIV counseling and testing programs are essential to render advances in treatment more accessible to HIV-infected persons).

²⁰⁴ See ASSOCIATION OF STATE & TERRITORIAL HEALTH OFFICIALS, GUIDE TO PUBLIC HEALTH PRACTICE: HIV PARTNER NOTIFICATION STRATEGIES 1-2 (1988) (stating that partner notification is essential because it allows at-risk individuals to obtain early preventative treatment, which in turn reduces the time frame for transmission of the disease to others); Ronald Bayer & Kathleen E. Toomey, *HIV Prevention and the Two Faces of Partner Notification*, 82 AM. J. PUB. HEALTH 1158, 1163 (1992) (noting that the need for partner notification is critical as AIDS trends shift to populations other than gay middle class men where awareness levels are much lower).

²⁰⁵ See Forbes, *supra* note 115, at 2 (noting that testing is not equivalent to treatment).

²⁰⁶ See Gostin & Hodge, *supra* note 26.

²⁰⁷ See Gostin et al., *supra* note 109, at 1164 (stating that although improved surveillance will increase accessibility to services for HIV-infected individuals, it will not remove all barriers).

²⁰⁸ See Gostin & Hodge, *supra* note 26.

D. Just Resource Allocation

Prevention services for HIV transmission are limited because the resources which support them are scarce.²⁰⁹ Under prevailing economic theories, scarce resources must be distributed efficiently to maximize the benefits.²¹⁰ The distribution of resources based on antiquated measures of need is economically unsound. Yet, this is exactly what occurs in the distribution of HIV prevention funds.

Historically, resource allocation of scarce funds for HIV/AIDS prevention has been based on AIDS surveillance data. This is particularly true for a major source of AIDS funding: the federal government.²¹¹ Federal prevention programs under the purview of the Ryan White Care Act²¹² and other federally authorized expenditures continue to be based on national AIDS data.²¹³ Such data have been used because they are universally available and provide a standardized, representative accounting of the number of persons with end-stage HIV disease.²¹⁴

Health care planning based on HIV rather than AIDS trends, however, would provide a more accurate assessment of factors affecting allocation decisions, namely the distribution of the infected population, the numbers of people needing access to treatment, and the kinds of providers offering treatment. HIV reporting may also help to secure additional funding to combat the epidemic, or at least to stem decreases in funding which may follow from recent trends suggesting AIDS deaths are declining.²¹⁵ Accurate estimates of the current status and future directions of HIV infection could mobilize

²⁰⁹ See Gostin et al., *supra* note 109, at 1163 (explaining that improved HIV surveillance would allow scarce resources to be directed to areas with the greatest needs).

²¹⁰ See, e.g., Gary D. Meyers & Simone C. Muller, *The Ethical Implications, Political Ramifications and Private Limitations of Adopting Sustainable Development as National and International Policy*, 4 BUFF. ENVTL. L.J. 1, 21 (1996) (noting that economics is a science that prescribes how to achieve maximum welfare).

²¹¹ Total federal appropriations for AIDS (including CDC Prevention, Ryan White Care Act, NIH Research, and Housing Opportunities for People With AIDS) during fiscal year 1997 amounted to 3.311 billion dollars, representing a 390.8 million dollar increase over fiscal year 1996. See *Congress Approves 13 Percent Increase in AIDS Spending*, 11 AIDS POLY & L. (BNA) 1, 8 (Oct. 18, 1996). Total federal appropriations during fiscal year 1996 amounted to 2.920 billion dollars. See *id.*

²¹² Ryan White Comprehensive AIDS Resources Emergency Act of 1990, 42 U.S.C. §§ 300ff to 300ff-111 (1994).

²¹³ See Gostin et al., *supra* note 109, at 1164 (indicating that the current benchmark is the development of AIDS, not HIV infection).

²¹⁴ See *id.* (arguing that more accurate data would be obtained through HIV surveillance).

²¹⁵ See *supra* notes 153-57 and accompanying text (discussing the decrease in AIDS deaths and AIDS opportunistic illnesses).

1998]

political opin
surveillance,
AIDS trends
cline in HIV
populations
is climbing c
Women, chil
ample, are b
extent of HIV
reported from
one percent
Americans (c
and young p
versus seven

Thus, alloc
It jeopardize
failing to pr
health servi
dollars conti
demic is dec
tion based on
tributing pre
is spreading.

Reliance o
also influenc
ing status of
is currently t

²¹⁶ In fact, am
the rate of HIV in
reported HIV from
1996 through Jun
compares poorly t
a 9.9% decrease
through June 199
id.

²¹⁷ See Patricia
American Public J

²¹⁸ See Gostin
example of a feder

²¹⁹ See *id.*

²¹⁹ See *id.*

eligible for Medicaid coverage an individual must be diagnosed with an end-stage illness instead of its causative agent.²²⁰ This creates hardships for many people with HIV infection and the community as a whole. Poor people with HIV must wait until they either become seriously immunologically impaired or develop opportunistic infections before they can receive Medicaid benefits.²²¹ State AIDS drug assistance programs are drastically under-funded, serving only a fraction of those who may be eligible.²²² Since HIV combination therapies (for example, HAART) are prohibitively expensive (averaging \$12,000 to \$18,000 annually),²²³ many persons who are infected may be excluded from treatment. As a result, untreated persons with HIV may have high levels of circulating virus rendering them more infectious, are less likely to live independently and maintain their employment, and are more likely to require costly hospital care in the future.²²⁴ Where HAART treatment has been shown to improve markedly clinical outcomes of the HIV positive, decisions about eligibility for government benefits cannot rationally continue to be based upon the CDC-defined condition known as AIDS.²²⁵

V. THE SOCIAL IMPACT OF HIV REPORTING

Support for HIV reporting based on legitimate public health justifications does not necessarily require its implementation on a national scale. Objections to HIV reporting from individualistic and public health perspectives must be considered. The most telling

objections to derive from potential breaches of privacy and societal

Public health officials have a single core concern: protecting people from HIV are advised to report their status and treatment to report their status tested or detected that at-risk individuals

A second concern is that individual autonomy and privacy are compromised by mandatory participation of persons in reporting, participating individuals are revealed, individual applications for health privacy breaches of privacy databases of Realistically, state, or federal equivalent re

²²⁰ Cf. Robert N. Swidler, *Special Needs Plans: Adapting Medicaid Managed Care for Persons with Serious Mental Illness or HIV/AIDS*, 61 ALB. L. REV. 1113, 1140-47 (1998) (documenting the efforts of the New York state legislature to incorporate HIV-positive individuals into Medicaid managed care plans operated in-state).

²²¹ See Robert Pear, *Medicaid May Be Extended to Early Treatment of AIDS*, N.Y. TIMES, June 1, 1997, at A20 (citing Vice President Gore's statement that a person must essentially develop full-blown AIDS before Medicaid benefits are forthcoming).

²²² See Steinbrook, *supra* note 187, at 780 (stating that while drug assistance funding has increased markedly in prior years, only 38,500 of the estimated 140,000 to 280,000 persons who may be eligible were served in December 1996).

²²³ See *HIV/AIDS and Medicaid: Standards of Care for New Therapies*, 10 MEDICAID PHARMACY BULL. 1, 1-6 (1996).

²²⁴ Cf. Pear, *supra* note 221, at A20 (describing the ramifications of extending Medicaid benefits only to those persons who develop AIDS).

²²⁵ See Donald P. Francis & James A. Singleton, *Reporting of HIV-1 Infection Through the Provision of Essential Services*, 6 J. AIDS 285, 286 (1993) (arguing that use of the term AIDS is prohibitive to providing essential prevention and treatment services); see also Steinbrook, *supra* note 187, at 780 (indicating that the Clinton administration is considering expanding Medicaid to cover low-income people with HIV).

²²⁶ See Gostin, "voluntary testing,"

²²⁷ See Forbes, encourages people from state lines, avoid fear of being involu

²²⁸ See AIDS AC OF THE KEY POLICY of guidelines to ens

²²⁹ See Gostin e may subject HIV-i care).

²³⁰ See *id.* (disc HIV registry as we purposes).

²³¹ See *id.* (noti tion).

agnosed with
This creates
e community
ey either be-
opportunistic
State AIDS
ded, serving
HIV combina-
ly expensive
sons who are
lt, untreated
virus render-
endently and
quire costly
ent has been
HIV positive,
not rationally
on known as

health justi-
tion on a na-
tionalistic and
most telling

Managed Care for
3, 1140-47 (1998)
HIV-positive indi-

AIDS, N.Y. TIMES,
must essentially

ance funding has
280,000 persons

ies, 10 MEDICAID

tending Medicaid

tion Through the
of the term AIDS
also Steinbrook,
dering expanding

objections to HIV surveillance are behavioral and social.²²⁶ They derive from individual concerns about privacy and the effect that potential breaches of confidentiality may have on voluntary testing and societal discrimination.²²⁷

Public health authorities and community representatives share a single core concern about HIV case reporting: that it may deter people from being tested and seeking care.²²⁸ Persons at risk for HIV are advised to undergo testing to receive needed counseling and treatment. If persons who are HIV positive are required by law to report their names to health officials, will they decline to be tested or delay seeking a physician? Some AIDS activists argue that at-risk individuals will go underground, refusing to be tested.

A secondary concern related to issues of privacy infringement is that individual fears of societal discrimination may also deter voluntary participation in public health programs. Societal discrimination of persons with HIV, despite strong anti-discrimination measures, remains a major problem in the United States.²²⁹ HIV reporting, particularly on a named basis, arguably subjects participating individuals to societal discrimination when their identities are revealed by public health authorities. Yet, to what degree is individual apprehension of discrimination stemming from public health privacy violations founded? Well-publicized examples of breaches of privacy resulting from the improper use of public health databases of individuals with HIV or AIDS foster these fears.²³⁰ Realistically, however, the privacy of health records held by local, state, or federal public health authorities are far more secure than equivalent records held in the private sector.²³¹

²²⁶ See Gostin et al., *supra* note 109, at 1164-65 (noting that such objections include "voluntary testing, privacy, and discrimination").

²²⁷ See Forbes, *supra* note 115, at 1-2 (stating that mandatory name-based reporting discourages people from obtaining testing). Forbes notes that many people are willing to cross state lines, avoid seeking medical treatment, and do without available social services due to fear of being involuntarily tested and reported. See *id.* at 2.

²²⁸ See AIDS ACTION FOUND., SHOULD HIV TEST RESULTS BE REPORTABLE? A DISCUSSION OF THE KEY POLICY QUESTIONS 2 (1993) (suggesting that the CDC review state submissions of guidelines to ensure confidentiality).

²²⁹ See Gostin et al., *supra* note 109, at 1165 (explaining that unauthorized disclosures may subject HIV-infected persons to discrimination in housing, employment, and health care).

²³⁰ See *id.* (discussing a health official in Florida who publicly revealed names from an HIV registry as well as instances in which the judiciary has ordered disclosure for litigation purposes).

²³¹ See *id.* (noting the more stringent protections afforded to government-held information).

Both of these concerns, voluntary testing and societal discrimination, hinge on privacy protections of public health information held by government at all levels. In general, such information is secure. Stringent laws protect HIV and AIDS databases from unauthorized dissemination and use.²³² Thus, why do HIV/AIDS organizations and individuals continue to distrust the security of governmentally-held information? Perhaps their doubts are the product of general distrust about governmental control of intensely private facts. These concerns are also likely because the reporting of HIV information to government is itself thought as an affront to personal dignity even in the absence of actual harm. In either case, HIV reporting cannot be implemented successfully without addressing legitimate privacy concerns. HIV reporting must be conducted in a manner which best protects individual privacy without sacrificing the accuracy and value of the information collected.

A. *The Impact on Voluntary Testing and Treatment: The Importance of Alternative Test Sites*

Effective public health policy relies on individuals to be voluntarily tested for HIV. Unlike the coercive testing used with other STDs in the past, individuals must give informed consent for HIV testing.²³³ Measures which tend to discourage individuals from testing, such as mandatory partner notification programs, are often opposed.²³⁴ Similar opposition has been expressed against HIV reporting, particularly named reporting.²³⁵ Fears of potential breaches of privacy inherent in the collection of private facts about HIV-infected persons are sometimes thought to provide a disincentive for at-risk individuals to be tested.²³⁶ Under this view, individuals would forego testing than have their names entered in a government database.

The community's argument that named reporting will drive the epidemic underground is based on two assumptions: (1) that at-

risk individuals
requirements
that all tes-
tion.²³⁷ Nei-
mains to be
may not be t
have yet to
reporting do
multi-state s
thirty-one pe
aware of cas
of state legal
behavior bec
Study resp
ing HIV test
studies empl
couraging vol
options at pu

²³⁷ See *Is There* (BNA) 1, 9 (Oct. 3 "set a timetable for

²³⁸ See Scott B. icy, 61 ALB. L. REV. ple at risk of HIV)

²³⁹ See, e.g., F. Those at Risk, 12 J

²⁴⁰ See *id.*

²⁴¹ See *id.*

²⁴² See Laura J. ficiency Virus Test and disadvantages The Impact of Ava (comparing testing Kathleen Irwin et States: A Decade of confidentiality has in Who Seek Anonymous AIDS 585, 585 (199 Comparison of Ind MED. J. 344, 344 (Carolina with resic lips, The Relations Use of HIV Testing name reporting and

²⁴³ See HIV TEST ACTION COALITION

²³² See Larry Gostin, *A Decade of a Maturing Epidemic: An Assessment and Directions for Future Public Policy*, 16 AM. J.L. & MED. 1, 1 (1990) (surveying state laws dealing with HIV information); Gostin, *supra* note 25, at 506-07 (discussing health information laws).

²³³ See Shelia Taub, *Doctors, AIDS, and Confidentiality in the 1990s*, 27 J. MARSHALL L. REV. 330, 331 (1994) (pointing out that the informed consent requirement is part of a legislative attempt to prevent discrimination).

²³⁴ See, e.g., Gostin & Hodge, *supra* note 26.

²³⁵ See *infra* notes 328-30 (discussing the objections).

²³⁶ See Gostin, *supra* note 25, at 491 (emphasizing the importance of informational privacy to the public health).

risk individuals are sufficiently informed about HIV reporting requirements to the point that their behavior is influenced; and (2) that all testing options necessarily require individual identification.²³⁷ Neither of these assumptions, however, is valid. Much remains to be discovered as to the reasons why individuals may or may not be tested for infectious disease.²³⁸ While definitive studies have yet to be published, preliminary data indicate that HIV case reporting does not provide a distinct disincentive to testing.²³⁹ A multi-state survey of 2387 persons at risk for HIV showed that only thirty-one percent of respondents in HIV reporting states were even aware of case reporting.²⁴⁰ Since most respondents were unaware of state legal requirements, it seems unlikely that they altered their behavior because of HIV reporting.

Study respondents also reported an increased likelihood of seeking HIV testing if anonymous testing were available.²⁴¹ Additional studies emphasize the importance of alternative test sites in encouraging voluntary testing.²⁴² Most states offer anonymous testing options at public health testing sites.²⁴³ Currently, only ten states

²³⁷ See *Is There a Viable Alternative to Name-Based HIV Reporting?*, 12 AIDS Pol'y & L. (BNA) 1, 9 (Oct. 31, 1997) [hereinafter *Viable Alternative Article*] (noting that the CDC has "set a timetable for releasing guidelines on recommended reporting practice").

²³⁸ See Scott Burris, *Law and the Social Risk of HIV Testing: Issues in Research and Policy*, 61 ALB. L. REV. 831, 831-34 (1998) (arguing that little is actually known about how people at risk of HIV perceive the social risks of testing).

²³⁹ See, e.g., F.M. Hecht et al., *Named Reporting of HIV: Attitudes and Knowledge of Those at Risk*, 12 J. GEN. INTERNAL MED. 108 (1997) (surveying the effects of HIV reporting).

²⁴⁰ See *id.*

²⁴¹ See *id.*

²⁴² See Laura J. Fehrs et al., *Trials of Anonymous Versus Confidential Human Immunodeficiency Virus Testing*, 2 LANCET 379, 379 (1988) (analyzing and discussing the advantages and disadvantages of anonymous testing); Douglas Hirano et al., *Anonymous HIV Testing: The Impact of Availability on Demand in Arizona*, 84 AM. J. PUB. HEALTH 2008, 2009 (1994) (comparing testing demands in Arizona from named reporting and anonymous testing); Kathleen Irwin et al., *The Acceptability of Voluntary HIV Antibody Testing in the United States: A Decade of Lessons Learned*, 10 J. AIDS 585, 585 (1990) (analyzing the impact confidentiality has in encouraging persons to seek testing); Susan M. Kegeles et al., *Many People Who Seek Anonymous HIV-Antibody Testing Would Avoid It Under Other Circumstances*, 4 J. AIDS 585, 585 (1990) (analyzing impacts of alternative testing sites); Pamela A. Meyer et al., *Comparison of Individuals Receiving Anonymous and Confidential Testing for HIV*, 87 S. MED. J. 344, 344 (1994) (comparing the impact of anonymous testing in Georgia and North Carolina with residents of South Carolina, where name reporting is used); Kathryn A. Phillips, *The Relationship of 1988 State HIV Testing Policies to Previous and Planned Voluntary Use of HIV Testing*, 7 J. AIDS 403, 406 (1994) (comparing testing patterns in states with name reporting and states with anonymous testing).

²⁴³ See HIV TESTING ACTION COALITION, STATEMENT OF THE NATIONAL HIV TESTING ACTION COALITION ON THE NECESSITY FOR MAINTAINING ANONYMOUS HIV TESTING SITES IN

do not offer such testing.²⁴⁴ Even in states where anonymous testing is not an option, individuals may purchase home collection testing kits over the counter at major drug stores to be tested anonymously.²⁴⁵ Private test kits, of course, may be inaccessible to persons without the means to pay for them.

While anonymous testing options arguably are available to many at-risk individuals in the United States, whether through government-supported alternative testing sites or through home collection kits, any recommendation for national HIV reporting should be joined with a requirement that all states provide confidential alternative test sites.²⁴⁶ Assuming there is a correlation between anonymous testing options and the willingness of some individuals to be tested, the stakes are simply too high. If individuals are deterred from seeking testing they may delay treatment which is critical in prolonging life expectancy and reducing infectiousness. In the absence of anonymous sites, persons at risk may seek testing at blood donation centers thus increasing the risk to the blood supply. Finally, without alternative test sites, HIV surveillance may be hampered by individuals who simply give false identifying information at confidential testing sites to assure their test is anonymous.²⁴⁷

Questions about the impact of anonymous testing options on HIV surveillance are another consideration. To what extent do these options skew surveillance by effectively exempting potentially HIV-infected individuals from reporting requirements? Certainly actual numbers of HIV-positive individuals reported to authorities de-

crease depe-
reporting, hov
individuals.
trends base
populations
poses so long
tual disease
cal proportio
within a giv
veillance thr

In additio
militate in f
mous HIV t
scribe the u-
risdictions v
cost-prohibit
supported ar
any realistic
a private ph
HIV reportir
options is so
where anony
dividuals m-
among repre
tics are disto
tifications fo

While the i
is largely un
most states (

ALL STATES 2 (1997) (arguing that anonymous testing is critical in encouraging individuals to seek testing).

²⁴⁴ These states are Alabama, Idaho, Michigan, Nevada, North Carolina, Ohio, South Carolina, South Dakota, Tennessee, and Wyoming. *See id.* at 3. Unfortunately, each of these states which do not offer anonymous testing sites also require name-based HIV reporting. *See id.*

²⁴⁵ *See, e.g.,* John G. Taylor, *HIV Home-Testing Kits Leave Counseling Gaps*, FRESNO BEE, Feb. 20, 1997, at B1 (discussing two versions of home testing).

²⁴⁶ *See* HIV TESTING ACTION COALITION, *supra* note 243, at 1 (stating that "the CDC must warn states with mandatory, name-based HIV reporting that their CDC funding will be jeopardized if full access to anonymous HIV testing is not maintained"); National Association of People with AIDS, *Policy Position Paper on Monitoring of the HIV Epidemic* (visited Feb. 5, 1998) <<http://hivinsite.vcsf.edu/topics/testing/2098.33a9.html>> (on file with author) ("The CDC must aggressively promote, expand and improve anonymous HIV testing in the United States. The availability of readily accessible anonymous testing is a necessary precondition/prerequisite for any maintenance and/or expansion of HIV surveillance in the United States.").

²⁴⁷ *See* HIV TESTING ACTION COALITION, *supra* note 243, at 2.

²⁴⁸ *See id.* at 3
tory name reporti

²⁴⁹ *See* Willard
and Interpreting
SURVEILLANCE, su
inherent weaknes
quently be detecte
consistent, incom
that occur infrequ

²⁵⁰ *See* Taylor, :
at risk individuals'

²⁵¹ *See supra* n
anonymous testing

²⁵² *See supra* n

ymous test-
ne collection
to be tested
accessible to

able to many
ough govern-
me collection
ng should be
dential alter-
tion between
e individuals
duals are de-
ent which is
fectiousness.
y seek testing
he blood sup-
veillance may
dentifying in-
test is anony-

ptions on HIV
t do these op-
entially HIV-
rtainly actual
uthorities de-

ging individuals to

olina, Ohio, South
ortunately, each of
ame-based HIV re-

Gaps, FRESNO BEE,

hat "the CDC must
nding will be jeop-
onal Association of
mic (visited Feb. 5,
with author) ("The
sting in the United
necessary precondi-
ance in the United

crease depending on the prevalence of anonymous testing.²⁴⁸ Reporting, however, is not merely based on the counting of infected individuals. It is the science of analyzing prevalence and incidence trends based on accurate measurements. Representative statistical populations of individuals with HIV may suffice for reporting purposes so long as representative populations are demonstrative of actual disease patterns and trends. Thus, provided that the statistical proportion of individuals who choose anonymous testing options within a given time period does not radically deviate, accurate surveillance through reporting can be accomplished.²⁴⁹

In addition to public health concerns, considerations of equity militate in favor of public access to government-supported anonymous HIV testing in all jurisdictions. Principles of fairness proscribe the unequal treatment of at-risk individuals in differing jurisdictions who desire anonymous testing. Home testing kits are cost-prohibitive for the poor.²⁵⁰ In jurisdictions where government-supported anonymous testing options are unavailable, the poor lack any realistic HIV-testing option without providing their identity to a private physician or public health authorities. Where national HIV reporting is conducted, the lack of uniform anonymous testing options in some jurisdictions may effect reporting trends.²⁵¹ States where anonymous tests effectively are unavailable to a class of individuals may under-report actual incidences of HIV infection among representative populations.²⁵² As a result, national statistics are distorted, undermining at least one of the public health justifications for HIV reporting, fair resource allocation.

While the impact of HIV reporting on individual testing behaviors is largely unknown, the existence of anonymous testing options in most states (and the recommendation of alternative testing options

²⁴⁸ See *id.* at 3 (illustrating the decrease in attendance at test sites in states with mandatory name reporting).

²⁴⁹ See Willard Cates, Jr. & G. David Williamson, *Descriptive Epidemiology: Analyzing and Interpreting Surveillance Data*, in PRINCIPLES AND PRACTICE OF PUBLIC HEALTH SURVEILLANCE, *supra* note 19, at 96 (emphasizing the importance of recognizing some of the inherent weaknesses in data collection). "Disease trends by time, place, and person can frequently be detected even with incomplete data. So long as the underreporting is relatively consistent, incomplete data can still be applied to derive useful inferences. For problems that occur infrequently, the need for completeness becomes more important." *Id.*

²⁵⁰ See Taylor, *supra* note 245, at B1 (stating that home tests "are too expensive for most at risk individuals").

²⁵¹ See *supra* notes 241-45 and accompanying text (discussing the impact of the lack of anonymous testing in some states).

²⁵² See *supra* notes 241-45 and accompanying text.

in all states as a precondition to national HIV reporting) help to satisfy fears that at-risk and infected individuals will avoid testing with the introduction of national HIV reporting.

B. Discrimination

Discrimination against persons with HIV and AIDS is a serious concern of infected individuals and society itself.²⁵³ Since HIV is not transmissible through casual contact,²⁵⁴ discrimination in the form of barriers to access to employment, public accommodations, and services is especially egregious and morally unwarranted.²⁵⁵ Discrimination against persons with HIV takes many other forms, including refusal to provide medical treatment,²⁵⁶ adverse employment decisions, and insurance companies' refusals to contract.²⁵⁷ Persons living with HIV/AIDS are stereotyped by society as homosexuals, drug users, or prostitutes, and relegated to a lesser social

²⁵³ See Ferdinand Schoeman, *AIDS and Privacy*, in *AIDS & ETHICS* 240, 241 (Frederic G. Reamer ed., 1992).

People infected with HIV have much to fear besides the disease. Because of the association of AIDS with promiscuity, primarily homosexual but also heterosexual, or the self-abandonment connected with intravenous (IV) drug usage, any adult with AIDS is suspected of degeneracy. . . . The level of public ignorance about the disease, the deficiency of scientific understanding surrounding aspects of its transmission, and the general hysteria about AIDS mean that people diagnosed as HIV positive must face social, economic, and medical hurdles no one with such dire medical prospects should have to confront. . . . A diagnosis of HIV infection, or even suspicion of this, is sufficient in some cases to deprive people of housing, employment, life and health insurance, social tolerance, routine and even emergency medical treatment like mouth-to-mouth resuscitation, schooling, social contacts, friendships, the right to travel in and out of countries—a social identity.

Id.; see also Mary Anne Bobinski, *Patients and Providers in the Courts: Fractures in the Americans with Disabilities Act*, 61 ALB. L. REV. 785, 786 (1998) (noting the AIDS epidemic has inspired a wide range of social and legal policies designed to minimize the risks of infection).

²⁵⁴ But cf. Ann Hardie, *CDC: Blood Is Factor in Case of HIV Transmission by Kissing "Social Kiss" Safe, Agency Still Says*, ATLANTA J. & CONST., July 13, 1997 at C7 (describing documented transmission of HIV through kissing).

²⁵⁵ See Ronald Bayer & Larry Gostin, *Legal and Ethical Issues in AIDS*, in *CURRENT TOPICS IN AIDS* 263, 264-65 (M.S. Gottlieb et al. eds., 1989) (commenting that "[d]iscrimination based upon an infectious condition can be as inequitable as discrimination based on other morally irrelevant grounds").

²⁵⁶ See Bobinski, *supra* note 253, at 797-98 (noting that the protections of the Americans with Disabilities Act [hereinafter ADA] and the Rehabilitation Act necessarily have been extended to patients with HIV).

²⁵⁷ See Burr, *supra* note 9, at 58 (describing how persons infected with AIDS have been discriminated against, including the refusal of nurses to treat them and insurance companies to cover their expenses); Larry Tye, *AIDS Patients' Partners Tracked, Informed Colorado Says Its Program Fights Spread of Disease While Protecting Privacy*, BOSTON GLOBE, Feb. 1, 1993, at 1 (noting, however, that such discrimination appears to be decreasing).

status. As tested fear through HI
crimination
strategies li
persons livi
should their

The law,
the HIV/AI
HIV/AIDS i
anti-discrim
federal level
abilities. Th
prohibits dis
and public se
tors and stat
1973²⁶² proh
and others re
lish national

²⁵⁸ See *infra* no

²⁵⁹ See, e.g., W
crimination again

²⁶⁰ 42 U.S.C. §§

²⁶¹ See Lawrence
248, 248 (1992).

²⁶² 29 U.S.C. §§

²⁶³ See *id.* § 794

²⁶⁴ The federal
may include persor
and in the provisio
civil suits requestin
investigate alleged vi
to treat HIV-infect
ADA. See *id.* Also
failure of a doctor t
normally treat sero
Separate or distinc
ment of HIV-positiv
viders also may not
als (such as a medi
HIV-negative), unle
which include virtu
hibited from discr
HIV-infected individ
nearly any aspect o
ployment Opportuni
legations. See *id.* §

porting) help to
will avoid testing

IDS is a serious
Since HIV is
mination in the
accommodations,
unwarranted.²⁵⁵
any other forms,
adverse employ-
s to contract.²⁵⁷
society as homo-
o a lesser social

240, 241 (Frederic G.

cause of the associa-
osexual, or the self-
it with AIDS is sus-
ease, the deficiency
and the general hys-
ist face social, eco-
should have to con-
s sufficient in some
urance, social toler-
to-mouth resuscita-
out of countries—a

arts: *Fractures in the*
ing the AIDS epidemic
the risks of infection).
mission by *Kissing*
1997 at C7 (describing

n AIDS, in *CURRENT*
) (commenting that
able as discrimination

ions of the Americans
essarily have been ex-

with AIDS have been
l insurance companies
d, *Informed Colorado*
OSTON GLOBE, Feb. 1,
easing).

status. As a result, individuals with HIV who are voluntarily tested fear discrimination should their identities be revealed through HIV reporting. Adequate legal protection against discrimination is critical to implementing successfully public health strategies like HIV reporting because it encourages participation of persons living with HIV/AIDS without fear of social consequences should their identities unintentionally be revealed.

The law, like the field of medicine, has matured in response to the HIV/AIDS epidemic. Legal protection for persons with HIV/AIDS is provided pursuant to disability²⁵⁸ and HIV-specific anti-discrimination laws.²⁵⁹ Legislatures at the local, state, and federal levels proscribe discrimination against persons with disabilities. The Federal Americans with Disabilities Act of 1990²⁶⁰ prohibits discrimination in employment, public accommodations, and public services, against persons with disabilities by private actors and state and local governments.²⁶¹ The Rehabilitation Act of 1973²⁶² prohibits such discrimination by the federal government and others receiving federal funding.²⁶³ Together these laws establish national anti-discrimination protection for persons with HIV.²⁶⁴

²⁵⁸ See *infra* notes 260-65 (discussing treatment of HIV by the ADA).

²⁵⁹ See, e.g., WASH. REV. CODE ANN. § 49.60.172 (West 1990) (making employment discrimination against HIV-infected persons unlawful).

²⁶⁰ 42 U.S.C. §§ 12101-12213 (1994).

²⁶¹ See Lawrence O. Gostin, *Disabilities Act and the US Health System*, 11 HEALTH AFF. 248, 248 (1992).

²⁶² 29 U.S.C. §§ 701-797.b (1994).

²⁶³ See *id.* § 794.

²⁶⁴ The federal acts specifically prohibit discrimination against disabled persons, which may include persons with HIV, in matters of employment, in places of public accommodation, and in the provision of public services. Persons discriminated against are entitled to bring civil suits requesting injunctive relief and request the United States Attorney General to investigate alleged violations. See 42 U.S.C. § 12188; 28 C.F.R. §§ 36.501-502 (1997). Refusals to treat HIV-infected individuals by virtually all health care providers are prohibited by the ADA. See *id.* Also prohibited by the ADA is the unequal provision of services (such as the failure of a doctor to treat an HIV-positive individual for certain conditions which he would normally treat sero-negative patients), unless necessary. See 42 U.S.C. § 12182(b)(1)(A)(iii). Separate or distinct provision of services (such as the use of special facilities for the treatment of HIV-positive persons) may not be used. See *id.* § 12182(b)(2)(A)(i). Health care providers also may not use eligibility criteria that effectually screen out HIV-infected individuals (such as a medical provider that requires prospective patients to demonstrate they are HIV-negative), unless necessary. See *id.* § 12182(b)(1)(B). Places of public accommodation, which include virtually every public business and government-operated facilities, are prohibited from discriminating against persons with HIV. See *id.* §§ 12181(7), 12131-12165. HIV-infected individuals who face unjustified discrimination at their place of employment in nearly any aspect of the employment relationship, can file complaints with the Equal Employment Opportunity Commission (EEOC), which is required to investigate merit-based allegations. See *id.* § 12112(a); 29 C.F.R. § 1630.4 (1994). After administrative remedies are

Many state and local governments also have laws that prohibit discrimination against persons with disabilities generally or against persons with HIV/AIDS specifically.²⁶⁵

A critically important question under disability discrimination law is whether persons in the early stages of HIV infection are covered. The definition of disability under the ADA focuses on the existence of a substantial impairment of a life function, or the perception or record of such impairment.²⁶⁶ Certainly, once HIV infection creates serious impairments, it becomes a disability.²⁶⁷ A question has arisen whether asymptomatic HIV infection alone constitutes a disability for the purposes of such laws.²⁶⁸ In the past, courts regularly found that pure asymptomatic HIV infection is a disability,²⁶⁹ but recent cases challenge these findings.²⁷⁰ This issue may

exhausted, a grievant can file a civil suit against the employer to demand equitable relief (such as reinstatement and back pay in cases of wrongful termination) and seek compensatory and punitive damages where the discrimination is shown to be intentional. *See id.* Housing discrimination against disabled persons, including those infected with HIV, is unlawful under a variety of federal, state, and local laws including the Fair Housing Act. *See* 42 U.S.C. §§ 3601-3631 (1994). Thus, landlords and real estate agents cannot discriminate against HIV-positive persons in the rental or sale of most dwellings, or risk being subjected to civil suit. *See id.* §§ 3613, 3610, 3614(a).

²⁶⁵ *See* Josephine Gittler & Sharon Rennert, *HIV Infection Among Women and Children and Antidiscrimination Laws: An Overview*, 77 IOWA L. REV. 1313, 1384 n.325 (1992) (listing state statutes regarding HIV anti-discrimination protections).

²⁶⁶ *See* 42 U.S.C. § 12102(2) (including within the definition of a disability either a physical or mental impairment).

²⁶⁷ *See* Doe v. Kohn Nast & Graf, P.C., 862 F. Supp. 1310, 1320-21 (E.D. Pa. 1994) (describing plaintiff's physical symptoms and concluding that plaintiff had a disability within the meaning of the ADA).

²⁶⁸ *See, e.g.,* Ennis v. National Assoc. of Bus. & Educ. Radio, Inc., 53 F.3d 55, 60 (4th Cir. 1995) (addressing the issue of an asymptomatic HIV infection).

²⁶⁹ *See* Wendy E. Parmet & Daniel J. Jackson, *No Longer Disabled: The Legal Impact of the New Social Construction of HIV*, 23 AM. J.L. & MED. 7, 16 (1997) ("[E]very reported decision from the mid-1980s up until the passage of the Americans with Disabilities Act in 1990 determined that both AIDS and, when presented, asymptomatic HIV infection constituted disabilities within the meaning of the Rehabilitation Act or similar state statutes.").

²⁷⁰ *See* Abbott v. Bragdon, 107 F.3d 934, 949 (1st Cir.), *cert granted*, 118 S. Ct. 554 (1997) (discussing a patient with HIV, who brought an ADA claim against her dentist who refused to treat her, was qualified as disabled); *Ennis*, 53 F.3d at 60 (overlooking overwhelming legislative history of the ADA that HIV infection constituted a disability to state in dicta that an asymptomatic HIV-positive child was not disabled under the individualized assessment required by the ADA); *Cortes v. McDonald's Corp.*, 955 F. Supp. 541 (E.D.N.C. 1996) (finding under individualized assessment that HIV-positive employee who was asymptomatic and appeared well was not disabled for the purposes of the ADA); *Doe*, 862 F. Supp. at 1321 (challenging the standard conception of HIV infection as a "disability" under the ADA, although ultimately agreeing it was in the case of an HIV-positive attorney); *see also* Parmet & Jackson, *supra* note 269, at 13-14 (scrutinizing Arthur Leonard's theory that the rationale for disability law is applicable to those persons infected but asymptomatic).

soon be resc
cently grani

The inter
levels is to
HIV are no
crimination
the possibil
National H
probable by
HIV-positiv
tabases.²⁷³
bases, at ai
uses or diss
below,²⁷⁵ is
purely from
are more pe

Communi
voluntary te
fected indivi
are concerne
intensely pr
sions of priv
munities and
dissuade oth
ernment wh

²⁷¹ *See* Abbott
matic, had a phys

²⁷² *See, e.g.,* 4:
to discrimination
persons from disc

²⁷³ *See* Gostin
the use of social s

²⁷⁴ *See id.*

²⁷⁵ *See infra* P.
nation).

²⁷⁶ However, F
persons with HIV
tance registries a
bases also contain
collected, stored,
in the private hea

soon be resolved by the United States Supreme Court which has recently granted certiorari in a case on point.²⁷¹

The intent of anti-discrimination laws at the federal and state levels is to create an environment in which persons infected with HIV are not subject to discrimination.²⁷² In reality, however, discrimination continues, causing infected persons to continue to fear the possibility that their condition may become known to others. National HIV reporting, it is argued, makes discrimination more probable by systematically collecting identifiable information about HIV-positive individuals and storing that information in central databases.²⁷³ This argument is based on the belief that HIV databases, at any level of government, are not secure from improper uses or dissemination.²⁷⁴ This belief, however, as we shall examine below,²⁷⁵ is unfounded. Resulting fears of discrimination arising purely from governmental collection of identifiable HIV information are more perception than reality.

C. Privacy

Community concerns about HIV reporting, that it may discourage voluntary testing and lead to or facilitate discrimination against infected individuals, center on the same issue: privacy. Individuals are concerned about breaches of privacy related to the collection of intensely private health information by the government.²⁷⁶ Invasions of privacy expose infected individuals within their local communities and may lead to discrimination. Threats of discrimination dissuade others from being tested. People, moreover, distrust government where it accumulates private facts about its citizens both

²⁷¹ See *Abbott*, 107 F.3d at 934 (holding that patient with the HIV virus, but asymptomatic, had a physical impairment making her disabled under the ADA).

²⁷² See, e.g., 42 U.S.C. § 12101 (1994) (providing remedies for disabled persons subjected to discrimination); WASH. REV. CODE ANN. § 49.60.172 (West 1996) (protecting HIV-infected persons from discrimination).

²⁷³ See Gostin et al., *supra* note 95, at 6 (noting the anxiety of many persons concerning the use of social security numbers as identifiers).

²⁷⁴ See *id.*

²⁷⁵ See *infra* Part V.C (discussing individuals' concerns about privacy and fear of discrimination).

²⁷⁶ However, HIV surveillance would not create unique privacy concerns. The names of persons with HIV infection are already accumulated in other databases such as drug assistance registries and public health registries for other reportable conditions. Medicaid databases also contain the names of HIV-positive individuals. In addition, sensitive HIV data are collected, stored, and widely used by insurers, managed care organizations, and researchers in the private health care sector. See Gostin et al., *supra* note 109, at 1165.

from a civil liberties and public health perspective. The challenge to public health authorities is to design and implement a national system of HIV reporting that is least intrusive to individual privacy yet efficacious.

1. Legal Rights to Privacy

Persons living with HIV/AIDS have potent reasons for desiring privacy, but to what degree is there a right to privacy? Do constitutional or statutory rights to individual privacy require public health authorities to respect individual confidential matters? Do privacy rights of individuals prevent government from collecting confidential information for the purpose of HIV reporting? The answers to these questions vary.

Constitutional claims to privacy made by persons are insufficient to defeat public health practices such as HIV reporting. While the United States Constitution does not expressly provide individuals with privacy rights, the Supreme Court has recognized a limited right to health informational privacy as a liberty interest within the Fifth and Fourteenth Amendments.²⁷⁷ Other courts have relied on

²⁷⁷ See, e.g., Gostin, *supra* note 25, at 495 (providing an in-depth discussion of the privacy rights of individuals in their health care information). In *Whalen v. Roe*, 429 U.S. 589 (1977), the Court considered whether the constitutional right to privacy was infringed by a state reporting law which required physicians to relay the names and other information of persons receiving prescriptions for certain addictive drugs to the state health department. See *id.* at 593-94. Writing for the majority, Justice Stevens found no unlawful violation of individual privacy rights as a result of the reporting requirement where the state had adequate standards and procedures to protect the privacy of the information. See *id.* at 598-604. The Court explained that the measures taken by the state health department, including limited access to information and the prevention of on-line interception of computer databases containing such information, were sufficient to protect individual privacy. See *id.* Rather than prescribing exacting constitutional standards to protect individual privacy, the Court deferred to the ability of governments to protect information which is private in nature, including health information. See *id.*; see also *Planned Parenthood v. Danforth*, 428 U.S. 52, 80 (1976) (appearing to recognize an independent right to informational privacy, but upholding reporting and record-keeping requirements that were reasonably directed to the preservation of maternal health and properly respected a patient's confidentiality). Four months preceeding its decision in *Whalen*, the Court acknowledged a narrow right to privacy in personal communications, although the Court again deferred to the ability of government sources to protect such privacy interests. See *Nixon v. Administrator of Gen. Servs.*, 433 U.S. 425, 465 (1977). Against a challenge by former President Nixon, the Court upheld the constitutionality of a federal statute directing the General Services Administration to take custody of presidential materials and to have them screened by federal archivists. See *id.* The Court based its opinion on the limited intrusion of the screening process, the appellant's status as a public figure, his lack of expectation of privacy in the overwhelming majority of materials, and the virtual impossibility of segregating the small quantity of private materials without comprehensive screening. See *id.* It emphasized that the statute's sensitivity to the

state cons
ther case,
larly allow
ministrati
against th
governmen
sonable se
tional gove
distribution
text of pul

President's legi
cretion sufficien
DeSanti, 653 F.
tend to a gene
Paul v. Davis 1
arrested for sh
that there was
such as an arre

²⁷⁸ See Falco
that the Alaska
tionships may b
under the Calif
nized as an asp
than a dozen sta
privacy interest
SMITH, COMPILA
constitutional p
Soroka v. Dayton
fornia's privacy
v. South Fla. Blo
to a blood donati

²⁷⁹ See *Nixon*.
est in subjectin
States v. Westin
tors to be balanc
vacy: (1) the typ
unauthorized dis
was generated; (2)
the degree of nee

²⁸⁰ See, e.g., E
financial disclosu
conflicts of intere
tating research a
Schachter v. Whi
mentation of sou

²⁸¹ See Gostin
ment's expressed
through the case

²⁸² Individuals
obtain a remedy

e challenge
a national
ual privacy

or desiring
to constitu-
public health
Do privacy
g confiden-
answers to

insufficient
While the
individuals
d a limited
within the
ve relied on

n of the privacy
U.S. 589 (1977),
ed by a state re-
sation of persons
ment. See *id.* at
on of individual
adequate stan-
: 598-604. The
cluding limited
databases con-
d. Rather than
the Court de-
e in nature, in-
h, 428 U.S. 52,
ravity, but up-
directed to the
ntiality). Four
right to privacy
of government
en. Servs., 433
ourt upheld the
stration to take
ivists. See *id.*
the appellant's
ing majority of
ivate materials
nsitivity to the

state constitutional provisions in support of such rights.²⁷⁸ In either case, constitutional privacy rights are limited. Courts regularly allow infringements on informational privacy through the administration of a flexible test, balancing the invasion of privacy against the strength of the governmental interest.²⁷⁹ Provided the government articulates a valid societal purpose²⁸⁰ and employs reasonable security measures, courts have not interfered with traditional governmental activities of health information collection and distribution.²⁸¹ Thus, the constitutional right to privacy, in the context of public health, is nominal.²⁸² This is especially true in in-

President's legitimate privacy interests and the unblemished record of the archivists for discretion sufficiently guarded against any infringement of personal privacy. See *id.*; cf. *J.P. v. DeSanti*, 653 F.2d 1080, 1090 (6th Cir. 1981) (holding that the right to privacy does not extend to a general right to nondisclosure of personal information). The Supreme Court in *Paul v. Davis* held that publication by the police department of the fact that a person was arrested for shoplifting did not raise a constitutional question, relying, in part, on the fact that there was no constitutional bar to the government publishing a record of an official act, such as an arrest. See 424 U.S. 693, 713 (1976).

²⁷⁸ See *Falcon v. Alaska Pub. Offices Comm'n*, 570 P.2d 469, 476 (Alaska 1977) (noting that the Alaska Constitution requires "a very high level of justification" before special relationships may be interfered); *People v. Stritzinger*, 668 P.2d 738, 742 (Cal. 1983) (noting that under the California Constitution "[t]he psychotherapist-patient privilege has been recognized as an aspect of the patient's constitutional right to privacy"). Since the 1970s, more than a dozen states have adopted constitutional amendments designed to protect a variety of privacy interests, including limitations on access to personal information. ROBERT ELLIS SMITH, *COMPILATION OF STATE AND FEDERAL PRIVACY LAWS* 17-18 (1981). Most of the state constitutional provisions only protect against breaches of privacy by government. See, e.g., *Soroka v. Dayton Hudson Corp.*, 1 Cal. Rptr. 2d 77, 83 (Ct. App. 1991) (recognizing that California's privacy provisions are applicable to both private and public employers); *Rasmussen v. South Fla. Blood Serv. Inc.*, 500 So. 2d 533, 536 (Fla. 1987) (denying an AIDS victim access to a blood donation organization's records).

²⁷⁹ See *Nixon*, 433 U.S. at 458 ("[A]ny intrusion must be weighed against the public interest in subjecting the Presidential materials . . . to archival screening."); see also *United States v. Westinghouse Elec. Corp.*, 638 F.2d 570, 578 (3d Cir. 1980) (enumerating five factors to be balanced in determining the scope of the constitutional right to informational privacy: (1) the type of record and the information it contains; (2) the potential for harm in any unauthorized disclosure; (3) the injury from disclosure to the relationship in which the record was generated; (4) the adequacy of safeguards to prevent nonconsensual disclosure; and (5) the degree of need for access, i.e., a recognizable public interest).

²⁸⁰ See, e.g., *Barry v. City of New York*, 712 F.2d 1554, 1560 (2d Cir. 1983) (finding city's financial disclosure law furthered a substantial state interest in deterring corruption and conflicts of interest); *Westinghouse*, 638 F.2d at 578-79 (noting strong public interest in facilitating research and investigations of National Institute for Occupational Safety and Health); *Schachter v. Whalen*, 581 F.2d 35, 37 (2d Cir. 1978) (finding information crucial to implementation of sound state policy of investigating licensed physicians for medical misconduct).

²⁸¹ See Gostin, *supra* note 25, at 497 (commenting that "[j]udicial deference to government's expressed need to acquire and use information is an unmistakable theme running through the case law").

²⁸² Individuals asserting a constitutional right to informational privacy are unlikely to obtain a remedy save in cases where the state fails to assert any significant interest or is

stances where, as with HIV reporting, government policies protect individual privacy to the degree possible and the uses of data are limited to the purposes for which they are collected.

Statutory protections of personal privacy generally do not override state reporting requirements. While the federal government has enacted several statutes and regulations to protect privacy of health information, such protections do not interfere with public health surveillance activities undertaken with due respect for personal privacy.²⁸³ Other federal legislation, however, limits the uses of identifiable information gathered under reporting requirements for purposes other than for which it is provided (namely, epidemiologic surveillance), and prevents the publication of such information in a manner which identifies subjects without their consent.²⁸⁴

particularly careless in disclosing highly sensitive information. See *Doe v. Borough of Barington*, 729 F. Supp. 376, 391 (D.N.J. 1990) (holding that a police officer violated a constitutional right to privacy by disclosing that a person was infected with HIV); *Woods v. White*, 689 F. Supp. 874, 876-77 (W.D. Wis. 1988) (extending constitutional right to privacy to disclosure of prisoner's HIV status by prison medical service personnel), *aff'd*, 899 F.2d 17 (7th Cir. 1990); *Carter v. Broadlawns Med. Ctr.*, 667 F. Supp. 1269, 1282 (S.D. Iowa 1987) (holding that giving chaplains open access to patient medical records violated privacy rights of patients).

²⁸³ Federal legislation such as the Privacy Act of 1974, 5 U.S.C. § 552(b)(1)-(3), (6) (1994), which requires federal agencies to utilize fair information practices with regard to the collection, use, or dissemination of systematized records, and the Freedom of Information Act of 1966 (FOIA), *id.* § 552, which exempts from governmental disclosure several categories of records which include health information, apply primarily to federal agencies, not necessarily state actors whose only federal connection is partial funding. Other federal regulations requiring privacy protections in relation to the treatment of persons for drug or alcohol dependency in federally-funded facilities, 42 U.S.C. § 290dd-2 (1994), and the administration of human subject research, 45 C.F.R. §§ 46.101, 46.404 (1997), simply do not apply to state reporting programs.

²⁸⁴ See 42 U.S.C.A. § 242m(d) (West Supp. 1997). This provision states, in relevant part: No information, if an establishment or person supplying the information or described in it is identifiable, obtained in the course of activities undertaken or supported under section [242(b) regarding research in health statistics, or 242k, regarding activities of the National Center for Health Statistics] may be used for any purpose other than the purpose for which it was supplied unless such establishment or person has consented . . . to its use for such other purpose; and in the case of information obtained in the course of health statistical or epidemiological activities under section [242b or 242k], such information may not be published or released in other form if the particular establishment or person supplying the information or described in it is identifiable unless such establishment or person has consented

Id. This statute, passed pursuant to the establishment of the Public Health Service which oversees the CDC through the Department of Health and Human Services, has been determined to apply to surveillance-based projects funded in whole or in part by the CDC. See 42 U.S.C.A. § 242k(m)(3) (Supp. 1997), concerning grants for the analysis of data on ethnic and racial populations, which states that "[p]rovisions of [42 U.S.C.A. § 242m(d)] do not apply to surveys or studies conducted by grantees under this subsection," absent other factors. The disallowance of the provisions of 42 U.S.C.A. § 242m(d) concerning grants for ethnic and ra-

States ha
including
formation
medical in
disclosing
ten conse
law,²⁸⁷ as

States l
privacy la
not preve
ized by st
purpose o
for the pu

These s
protection
duty of co
disclose th
protection:
this conte
dence of i
porting pr
privacy int

cial studies ne
veillance proce

²⁸⁵ See, e.g.,

²⁸⁶ See, e.g.,

²⁸⁷ See CAL.

70.02.005-.904
version of the
REV. CODE AN
which is ident
70.02.010(6)) b
tion. A subseq
allows a health
to "federal, sta
required by la
with state or f
protect the publi

²⁸⁸ See Tbl. 1

²⁸⁹ See Haro
islative Option
with HIV-relati

²⁹⁰ See *supra*

²⁹¹ See *supra*

es protect
f data are

not over-
overnment
privacy of
ith public
ct for per-
s the uses
uirements
, epidemi-
n informa-
consent.²⁸⁴

rough of Bar-
ted a constitu-
oods v. White,
privacy to dis-
9 F.2d 17 (7th
) Iowa 1987)
privacy rights

(3), (6) (1994),
d to the collec-
-ation Act of
l categories of
not necessarily
regulations re-
or alcohol de-
ministration of
ly to state re-

relevant part:
described in
d under sec-
ivities of the
an the pur-
ented . . . to
he course of
. such infor-
ishment or
such estab-

Service which
as been deter-
CDC. See 42
on ethnic and
o not apply to
r factors. The
ethnic and ra-

States have enacted information privacy protections in many forms, including laws similar to the Privacy Act²⁸⁵ and the Freedom of Information Act (FOIA).²⁸⁶ A few states have passed comprehensive medical information statutes that prohibit medical providers from disclosing identifiable health information without a patient's written consent, unless the disclosure is required or authorized by law,²⁸⁷ as with reporting requirements.²⁸⁸

States have also passed disease specific privacy laws, including privacy laws concerning HIV infection or AIDS.²⁸⁹ These laws do not prevent HIV reporting because reporting is expressly authorized by state statutes.²⁹⁰ Courts are likely to defer to the specific purpose of reporting statutes of collecting vital health information for the purpose of controlling contagious diseases like HIV/AIDS.

These same conclusions can be reached concerning common law protections. As previously discussed,²⁹¹ the common law imposes a duty of confidentiality on certain health care professionals not to disclose the confidences of their patients. As with statutory privacy protections, a primary exception to the duty of confidentiality in this context is reporting requirements. Thus, reporting the incidence of infectious disease overrides privacy interests where reporting practices are statutorily mandated and respectful of the privacy interests of infected persons.

cial studies negatively implies the application of the section to all other federally-funded surveillance procedures not otherwise exempted.

²⁸⁵ See, e.g., N.Y. PUB. OFF. LAW §§ 91-99 (McKinney 1988 & Supp. 1998).

²⁸⁶ See, e.g., MISS. CODE ANN. §§ 25-61-1 (1991 & Supp. 1997).

²⁸⁷ See CAL. CIV. CODE §§ 56-56.37 (West 1982 & Supp. 1995); WASH. REV. CODE ANN. §§ 70.02.005-.904 (West 1992 & Supp. 1996). Legislation in Washington, which has passed a version of the Uniform Health-Care Information Act, is demonstrative on this point. WASH. REV. CODE ANN. § 70.02.020 prohibits the disclosure of health care information (information which is identifiable to a patient and directly relates to the patient's health care, *id.* at § 70.02.010(6)) by a health care provider to any person without the patient's written authorization. A subsequent provision of the Act, WASH. REV. CODE ANN. § 70.02.050(2)(a), however, allows a health care provider to disclose such information without a patient's authorization to "federal, state, or local public health authorities, to the extent the health care provider is required by law to report health care information; when needed to determine compliance with state or federal licenser, certification or registration rules or laws; or *when needed to protect the public health.*" *Id.* (emphasis added).

²⁸⁸ See Tbl. A.

²⁸⁹ See Harold Edgar & Hazel Sandomire, *Medical Privacy Issues in the Age of AIDS: Legislative Options*, 16 AM. J.L. & MED. 155, 163 (1990) (examining state legislation dealing with HIV-related problems in medical privacy laws).

²⁹⁰ See *supra* Part II.A; Tbl. A.

²⁹¹ See *supra* Part I.B.

2. Privacy and Security in the Maintenance and Use of HIV Registries

While individual privacy rights do not invalidate reporting practices per se, public health authorities have strong incentives for implementing privacy and security protections of reporting registries. Constitutional and statutory privacy rights require that government respect personal privacy in holding information and that such information be securely maintained.²⁹² As well, protection of sensitive information contained in an HIV registry is important toward securing public confidence in the public health system.

Although public health departments have a strong history of maintaining the confidentiality of reported information, community anxieties have been heightened by well-publicized and exceptional invasions of privacy. The American Civil Liberties Union (ACLU) cites reports that thieves stole a computer containing the names of sixty persons with AIDS in Sacramento, California²⁹³ and that a log of hundreds of people tested for HIV "vanished" from a public health clinic in New York.²⁹⁴ In Florida, a health official publicly revealed names from an HIV registry without authorization.²⁹⁵ Courts have occasionally ordered HIV data to be disclosed for the purposes of litigation.²⁹⁶ A few state legislatures have abused surveillance for political purposes. Illinois enacted, but never implemented, legislation requiring the state health department to identify HIV-positive health care workers by cross matching the state AIDS registry against health care licenser records.²⁹⁷ South Carolina health authorities legislatively are required to cross-check prospective and existing public school teachers against state HIV/AIDS databases.²⁹⁸

Although concerning, these examples and others are the rare exception rather than the norm. The CDC reports that since 1981

²⁹² See Privacy Act of 1974, 5 U.S.C. § 552(b) (1994); see also *supra* note 282 (listing cases which relied on the constitutional right to informational privacy).

²⁹³ See Richard C. Paddock, *Thieves Steal Computer Containing Confidential List of 60 AIDS Victims*, L.A. TIMES, July 9, 1987, at A3.

²⁹⁴ See Log, *Said To List AIDS Test-Takers, Is Lost*, N.Y. TIMES, Apr. 23, 1987, at A21.

²⁹⁵ See Sue Landry, *AIDS List Is Out: State Investigating Breach*, ST. PETERSBURG TIMES, Sept. 20, 1996, at A1 (reporting the unauthorized discovery of 4000 AIDS victims).

²⁹⁶ See *Tarrant County Hosp. Dist. v. Hughes*, 734 S.W.2d 675, 677 (Tex. App. 1987) (holding physician-patient privilege inapplicable to a discovery order).

²⁹⁷ See 720 ILL. COMP. STAT. 5/12-18 (West 1991).

²⁹⁸ See Barron et al., *supra* note 33, at 399 (reviewing South Carolina's laws concerning HIV/AIDS and public school teaching).

there has b
AIDS repor
ing named-
tections ap
records ma
particularly to
that states
ported heal
vacy legisla
tion.³⁰² Th
currently a
state public
data in pub
offers confi
hibiting the
pose other t
of the inform
maintain th
violation of
to criminal

3. Ethical Is

There is a
that no amc
ernment ho
Their claim

²⁹⁹ See CENTER
SERVS., THE ROL
(1998) (commenti

³⁰⁰ See Gostin,
O. Gostin et al., *T
on Health Inform
have some require*

³⁰¹ See Whalen
porting of prescrip
tients' identities w
note 277 (discussi
tional privacy).

³⁰² See Edgar &
tion).

³⁰³ See *supra* Pe

³⁰⁴ See, e.g., N.Y.
criminal penalties

IV

orting prac-
tives for im-
g registries.
hat govern-
nd that such
ion of sensi-
tant toward

g history of
, community
, exceptional
ion (ACLU)
he names of
nd that a log
om a public
cial publicly
orization.²⁹⁵
losed for the
abused sur-
never imple-
nent to iden-
ng the state
South Caro-
ss-check pro-
te HIV/AIDS

the rare ex-
t since 1981

282 (listing cases

dential List of 60

1987, at A21.
TERSBURG TIMES,
ctims).
(Tex. App. 1987)

s laws concerning

there has been only one reported breach of confidentiality of a state AIDS reporting system (Florida), with no known breaches concerning named-based HIV surveillance.²⁹⁹ Stringent legal privacy protections apply to governmentally-held health information (including records maintained by state and local health departments) and particularly to HIV data.³⁰⁰ The United States Supreme Court requires that states provide reasonable levels of privacy and security for reported health data.³⁰¹ Most states have enacted HIV specific privacy legislation that imposes stricter standards for HIV information.³⁰² The CDC and other federal and interest organizations currently are developing guidelines in the form of a uniform model state public health privacy statute to further protect sensitive HIV data in public health departments. Finally, the federal government offers confidentiality assurances for HIV/AIDS surveillance, prohibiting the use of personally identifiable information for any purpose other than that for which it was provided (unless the supplier of the information has consented to an alternate use).³⁰³ Failure to maintain the confidentiality of individuals in reporting registries in violation of these legal protections may subject responsible persons to criminal and civil sanctions.³⁰⁴

3. Ethical Issues Concerning Privacy

There is a perception among many AIDS and civil liberties groups that no amount of legal protection is satisfactory where the government holds highly-sensitive information about individuals. Their claim is grounded in two related ethical beliefs: (1) that the

²⁹⁹ See CENTERS FOR DISEASE CONTROL & PREVENTION, U.S. DEP'T OF HEALTH & HUMAN SERVS., *THE ROLE OF HIV SURVEILLANCE AS U.S. ENTERS NEW ERA IN THE EPIDEMIC* 1, 3 (1998) (commenting on the importance of HIV infection case surveillance).

³⁰⁰ See Gostin, *supra* note 25, at 459 (noting the examples of privacy breaches); Lawrence O. Gostin et al., *The Public Health Information Infrastructure: A National Review of the Law on Health Information Privacy*, 275 JAMA 1921, 1921 (1996) (noting that almost all states have some required protection for governmentally-maintained health information).

³⁰¹ See *Whalen v. Roe*, 429 U.S. 589, 605 (1977) (upholding a statute which required reporting of prescriptions written by physicians, on the ground that public disclosure of patients' identities was prohibited, and access to forms was sufficiently limited); see also *supra* note 277 (discussing the Supreme Court's recognition of a limited right to health informational privacy).

³⁰² See Edgar & Sandomire, *supra* note 289, at 155 (examining medical privacy legislation).

³⁰³ See *supra* Part V.C.1.

³⁰⁴ See, e.g., N.Y. PUB. HEALTH LAW § 2783 (McKinney 1993) (providing for both civil and criminal penalties for failing to maintain confidentiality).

reporting of HIV test results, demographics, and risk behaviors to government agencies constitutes a breach of trust;³⁰⁵ and (2) that HIV reporting violates the ethical principles of individual autonomy and dignity.³⁰⁶ Each of these arguments has considerable force, but they fail to recognize the positive value of public health surveillance to the population as a whole. They also fail to recognize the strong privacy protections provided by public health authorities particularly when compared with existing privacy protection in the health care system.

Government must maintain a level of trust among citizens through the maintenance of ethically sound practices.³⁰⁷ A relationship built on trust requires the population to believe that its government will act in ways that respect persons as individuals.³⁰⁸ Where government accumulates identifiable, highly-sensitive information about its citizens without their tacit approval, as through reporting requirements, a breach of trust arises. However, an individualistic argument against named-based reporting fails to acknowledge the broader scope of public health ethics. While respectful of individual rights, public health ethics looks to the interests of society as a whole.³⁰⁹ Where government policies are not simply paternalistic, but achieve compelling public health interests and are respectful of individual rights, they may take precedence.³¹⁰ Information gathered pursuant to reporting requirements is held privately and securely, and is used exclusively by government to monitor epidemiologic trends in furtherance of public health. Thus, while reporting requirements may affect a relationship of trust between the government and some citizens, most of the population

³⁰⁵ See Fox, *supra* note 27, at 11 (arguing that the controversy over required reporting is a political problem).

³⁰⁶ See *id.* at 15 (stating that reporting requires a loss of anonymity, including making others aware of the patient's sexual contacts).

³⁰⁷ See Robert A. Hahn, *Ethical Issues*, in *PRINCIPLES AND PRACTICE OF PUBLIC HEALTH SURVEILLANCE*, *supra* note 19, at 175, 188 ("The scale and significance of public health surveillance demand scrupulous and ongoing attention to ethics as well as to science.").

³⁰⁸ See James F. Childress, *Who Shall Live When Not All Can Live*, in *BIOETHICS: AN INTRODUCTION TO THE HISTORY, METHODS, AND PRACTICE* 19, 19-27 (Nancy S. Jecker et al. eds., 1997) (arguing that each individual should have an equal chance to receive scarce medical resources).

³⁰⁹ See Lappe, *supra* note 1, at 183 (stating that "public health ethics deal with collections of individuals, and hence are more concerned with community rights and those of society as a whole").

³¹⁰ See *id.* (noting "[p]roblems arise when the cumulative impacts of [individualized] decisions exceeds a certain threshold and begins to affect the public health or environment generally").

understand
benefits to

At-risk
privacy³¹¹
status in g
ples of aut
right to en
restrictions
in self-cho
information
HIV/AIDS
herent priv
to public d
forded to H-
based repor

From a n
terests in a
not necessa
transmissio
are, or at l

³¹¹ See Hahn, Privacy is the
his thoughts,
includes prote
formation to o
Id.

³¹² See Alberts
of the [doctor-pat
hered to in most
ing advice and tr
1982))). Confider
fected with HIV,
courage, and the

³¹³ See TOM L
120 (4th ed. 1994
vacy, connoting o
individual autono
that autonomous

³¹⁴ See Editoria
that AIDS activist
information is lea
³¹⁵ See Fox, *sup*
society is threat
States.").

³¹⁶ See Hahn, s
lines for Epidemic

behaviors to
and (2) that
al autonomy
le force, but
surveillance
e the strong
ties particu-
n the health

ong citizens
;.³⁰⁷ A rela-
ieve that its
individuals.³⁰⁸
sensitive in-
l, as through
ver, an indi-
fails to ac-
While respect-
e interests of
ot simply pa-
ests and are
ice.³¹⁰ Infor-
is held pri-
nent to moni-
alth. Thus,
of trust be-
e population

red reporting is a

including making

PUBLIC HEALTH
public health sur-
eience.").

BIOETHICS: AN
y S. Jecker et al.
eive scarce medi-

al with collections
ose of society as a

lividualized] deci-
environment gen-

understands the need to forego some level of privacy for health benefits to the community as a whole.

At-risk and infected persons also have strong ethical claims to privacy³¹¹ of their medical diagnosis, records, and their health status in general.³¹² These claims are based on normative principles of autonomy and dignity. Autonomous individuals have the right to engage in behaviors of their choosing without unwarranted restrictions.³¹³ Preserving human dignity and the right to engage in self-chosen behaviors requires individual control over personal information and the decisionmaking process. Persons living with HIV/AIDS claim that mandatory HIV reporting infringes their inherent privacy interests where it subjects their private information to public disclosure.³¹⁴ Regardless of the privacy protections afforded to HIV reporting data, the crux of their objections to named-based reporting is the simple loss of anonymity.³¹⁵

From a normative perspective, however, the infected persons' interests in autonomy are not absolute. Preserving autonomy does not necessarily override the interests of society to prevent the transmission of disease. Governmental interests in HIV reporting are, or at least should be, beneficent in nature.³¹⁶ Information

³¹¹ See Hahn, *supra* note 307, at 177.

Privacy is the duty to respect a person's right of determining, ordinarily, to what extent his thoughts, sentiments, and emotion shall be communicated to others Privacy includes protection from unwanted intrusions, and from the divulgence of personal information to others. The right to privacy may derive from respect for autonomy.

Id.

³¹² See *Alberts v. Devine*, 479 N.E.2d 113, 118-19 (Mass. 1985) (noting "the confidentiality of the [doctor-patient] relationship is a cardinal rule of the medical profession, faithfully adhered to in most instances, and thus has come to be justifiably relied upon by patients seeking advice and treatment," (quoting *MacDonald v. Clinger*, 446 N.Y.S.2d 801, 802 (App. Div. 1982))). Confidentiality is a vital concern to STD-positive individuals, particularly those infected with HIV, because of the need to obtain medical services, which confidentiality encourages, and the threat of societal discrimination, which confidentiality protects them from.

³¹³ See TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 120 (4th ed. 1994). These interests can be defined in terms of privacy and knowledge. Privacy, connoting one's control over the intimacies of personal identity, is a key component of individual autonomy. See Schoeman, *supra* note 253, at 242. Another is the requirement that autonomous individuals act with knowledge of factors which affect them personally.

³¹⁴ See Editorial, *Keeping Track of HIV Cases*, BOSTON GLOBE, Oct. 25, 1997, at A4 (noting that AIDS activists disagree with reporting to the state because of the stigma attached when information is leaked to the public).

³¹⁵ See Fox, *supra* note 27, at 15 ("Many gay men assert that their anonymity in a hostile society is threatened by disease reporting as it is practiced everywhere in the United States.").

³¹⁶ See Hahn, *supra* note 307, at 178-79, citing Tom L. Beauchamp et al., *Ethical Guidelines for Epidemiologists*, 44 J. CLINICAL EPIDEMIOLOGY 151 (1994) noting that among the

gleaned from reporting requirements can be used to benefit persons with HIV infection and others directly (through linking of HIV-positive individuals with partner notification support services) or indirectly (through administration of public health strategies or resource allocation).³¹⁷ A person with HIV infection cannot sustain an absolute ethical claim that maintaining her privacy at all costs justifies the failure to protect others from potential harm. The overwhelming interests of public health authorities in reliable surveillance data support HIV reporting from a normative perspective.

The corresponding ethical obligation of public health authorities to do no harm (the principle of nonmaleficence)³¹⁸ requires that authorities conduct surveillance activities in a manner which is least intrusive to individuals as possible, without negating essential public health ends.³¹⁹ Where the evils of HIV reporting stem from potential invasions of individual privacy, public health officials have the obligation to take all measures possible to assure privacy and security. This includes ensuring that private information is handled responsibly, that identifiable information is not distributed for purposes beyond that for which it is collected, and that information is made non-identifiable as soon as possible.³²⁰ Where these protections are instituted as part of meaningful surveillance, the incidental infringement of individual privacy is ethically justified.

VI. THE "NAMES DEBATE": NAMED REPORTING VERSUS UNIQUE IDENTIFIERS

We have sought to demonstrate that HIV reporting, to be successful, must be implemented in a manner that respects individual privacy without significantly limiting the utility of surveillance. Most public health authorities and gay and civil liberties groups agree that HIV reporting is an important public health objective.³²¹ Under debate is the means through which HIV reporting is accom-

ethical responsibilities of public health practitioners is the obligation to conduct surveillance, including reporting, for the benefit of the public).

³¹⁷ See Hahn, *supra* note 307, at 181.

³¹⁸ See *id.* at 177 (explaining that the principle of nonmaleficence might be viewed as the first tenet of beneficence—in order to benefit others, one must avoid harming them).

³¹⁹ See *id.* at 181.

³²⁰ See *id.* at 182-83.

³²¹ See Lynda Richardson, *AIDS Group Urges New York To Start Reporting of H.I.V.*, N.Y. TIMES, Jan. 13, 1998, at A1 (announcing the new position of the nation's leading AIDS service agency, which now supports confidential reporting of HIV-positive individuals to the state health department).

plished, with reporting rel identifying identifying on a nume cases of HI

Public he of named has traditi cluding AI tions of rep ual privac efficient, le HIV diseas

Gay and ject the use tifier.³²⁸ N discourages reporting b vacy of HI other priva the challen high numb to use, it is a unique ic porting, it

³²² See *id.*

³²³ See *id.*

³²⁴ See *id.*

³²⁵ See *id.*

³²⁶ See Fox, of STDs as earl Board of Health

³²⁷ See *id.* at

³²⁸ See Rich position on H.I. posed to reporti "fin separate r American Civil of name-based r

³²⁹ See Amer dence shows na

³³⁰ See *id.* at

³³¹ See *id.* at

³³² See *id.*

benefit persons
ing of HIV-
services) or
tegies or re-
t sustain an
all costs jus-
t. The over-
able surveil-
pective.
authorities
quires that
er which is
ing essential
g stem from
lth officials
sure privacy
formation is
t distributed
hat informa-
Where these
eillance, the
justified.

IS UNIQUE

o be success-
dividual pri-
lance. Most
roups agree
ative.³²¹ Un-
g is accom-

luct surveillance,

be viewed as the
; them).

g of H.I.V., N.Y.
ing AIDS service
uals to the state

plished, whether by name or by unique identifier (UI). Named reporting relies on the disclosure of an individual's name and other identifying characteristics.³²² Reporting by unique identifier strips identifying information from a reporting record,³²³ relying instead on a numeric code (intended to be unique for each person) to report cases of HIV infection.³²⁴

Public health authorities (with some exceptions) advocate the use of named reporting for several reasons.³²⁵ First, named reporting has traditionally been used with other STD reporting practices, including AIDS reporting.³²⁶ Second, they argue that privacy protections of reporting data are sufficient to prevent breaches of individual privacy.³²⁷ Third, named reporting is demonstrably more efficient, less costly, and more effective in tracking incidences of HIV disease.

Gay and civil liberties groups (with some exceptions) soundly reject the use of named reporting in favor of reporting by unique identifier.³²⁸ Named reporting, it is contended, is "bad policy" because it discourages individuals from being tested for HIV.³²⁹ They support reporting by unique identifiers because it better protects the privacy of HIV-infected persons, virtually eliminating the need for other privacy protections of government-held HIV data.³³⁰ Against the challenge that unique identifier systems result in an excessively high number of duplicates and are difficult for health care workers to use, it is contended that the reporting information obtained from a unique identifier system is still accurate enough.³³¹ Named reporting, it is correctly noted, results in duplication as well.³³² The

³²² See *id.*

³²³ See *id.*

³²⁴ See *id.*

³²⁵ See *id.*

³²⁶ See Fox, *supra* note 27, at 12 (noting that New York City began mandatory reporting of STDs as early as 1911, with physicians confidentially reporting patients with STDs to the Board of Health).

³²⁷ See *id.* at 15.

³²⁸ See Richardson, *supra* note 321, at B6 ("[M]any advocacy groups have softened their position on H.I.V. reporting Most organizations, however, have remained publicly opposed to reporting . . . names."); *Viable Alternative Article*, *supra* note 237, at 1 (stating that "[i]n separate position statements, the National Association of People with AIDS and the American Civil Liberties Union came out in favor of the use of unique identifiers . . . instead of name-based reporting").

³²⁹ See American Civil Liberties Union, *supra* note 119, at 3 (stating that available evidence shows named reporting does discourage individuals from being tested).

³³⁰ See *id.* at 10.

³³¹ See *id.* at 13.

³³² See *id.*

purpose of HIV reporting is not to count every last person, but to compute reliable prevalence and incidence rates in communities. Advocates suggest that unique identifier systems accomplish this end.³³³

Privacy principles mandate that public health information must be the narrowest in content, the least identifiable and sensitive, and disclosed to the fewest persons as reasonably necessary to achieve the public health purpose.³³⁴ Consequently, HIV surveillance that could be conducted as, or more effectively, without revealing an individual's identity is preferred to named reporting. The problem is that unique identifier systems have not been shown to work as well for the same costs as named reporting systems in the United States.³³⁵ In relation to qualitative attributes of surveillance systems, simplicity³³⁶ and acceptability,³³⁷ UI systems fail in comparison to named reporting.

Since 1994, two states, Maryland³³⁸ and Texas,³³⁹ have conducted HIV surveillance for all populations using non-named unique identifier systems.³⁴⁰

³³³ See *Viable Alternative Article*, *supra* note 237, at 1 (suggesting that a unique identifier system "would enable policy makers to obtain the epidemiological data they need without sacrificing confidentiality").

³³⁴ See Gostin et al., *supra* note 109, at 1165 (citing Lawrence O. Gostin et al., *The Public Health Information Infrastructure: A National Review of the Law on Health Information Privacy*, 275 JAMA 1921, 1921-27 (1996), and discussing the needed protections to ensure information remains confidential).

³³⁵ In contrast, countries such as Australia, Denmark, and England routinely use or have considered using coded, non-named HIV surveillance systems. See Ann M. McDonald et al., *A National Surveillance System for Newly Acquired HIV Infection in Australia*, 84 AM. J. PUB. HEALTH 1923, 1924 (1994) (discussing Australia); Else Smith et al., *Mandatory Anonymous HIV Surveillance in Denmark: The First Results of a New System*, 84 AM. J. PUB. HEALTH 1929, 1930-31 (1994) (discussing Denmark); Stephen Morris et al., *The Costs and Effectiveness of Surveillance of Communicable Disease: A Case Study of HIV and AIDS in England and Wales*, 18 J. PUB. HEALTH MED. 415, 419 (1996) (discussing England). However, the lower rate of HIV infection in these countries and the structure of their health care systems limit the application of their methods to surveillance in the United States. For discussion concerning the HIV reporting systems in Australia and Denmark, see John W. Ward et al., *Annotation: What Will Be the Role of HIV Infection Reporting?*, 84 AM. J. PUB. HEALTH 1888, 1888 (1994).

³³⁶ See Douglas N. Klaucke, *Evaluating Public Health Surveillance*, in PRINCIPLES AND PRACTICE OF PUBLIC HEALTH SURVEILLANCE, *supra* note 19, at 158, 164 ("Simplicity of a surveillance system refers both to its structure and to its ease of operation. Surveillance systems should be as simple as possible, while still meeting their objectives.")

³³⁷ See *id.* ("Acceptability reflects the willingness of individuals and organizations to participate in the surveillance system.")

³³⁸ See Centers for Disease Control and Prevention, *Evaluation of HIV Case Surveillance Through the Use of Non-Name Unique Identifiers—Maryland and Texas, 1994-1996*, 46 MORBIDITY & MORTALITY WKLY. REP. 1254, 1255 (1998) (describing the Maryland UI system); see also Liza Solomon, *The Role of (Non-Name) Unique Identifiers in Case Surveillance*,

tifiers.³⁴⁰ In the last four birth date and son's gender. The CDC has found that the number of systems are poor accept and testing in correctly taining sufficient care provided. The Security number reported.³⁴⁴ do not necessarily components 20,000 case

in Consultation
veillance in the

³³⁹ See Center
the Texas UI sy
Surveillance, in
AIDS Case Sur
with author).

³⁴⁰ For a general
supra note 115,
for lab-based rep
8 (reporting how

³⁴¹ See *Viable*
fier is calculated
born on January
010160-21.

³⁴² See Center

³⁴³ See *Viable*
ten left out of the

³⁴⁴ See *id.* at
cant improvement
inaugural year, 8
In Texas, the init

³⁴⁵ Health care
provide their Soc
Social Security n
tant to collect an
expensive reprogr

erson, but to
ommunities.
mplish this

nation must
d sensitive,
necessary to
HIV surveil-
without re-
d reporting.
been shown
; systems in
utes of sur-
systems fail

e conducted
unique iden-

unique identifier
ey need without

et al., *The Public
Health Information
Systems to ensure*

nely use or have
McDonald et al.,
ralia, 84 AM. J.
andatory Anony-
84 AM. J. PUB.
, *The Costs and
IV and AIDS in
England*). How-
their health care
States. For dis-
e John W. Ward
J. PUB. HEALTH

PRINCIPLES AND
mplicity of a sur-
veillance sys-

izations to par-

ise Surveillance
1994-1996, 46
aryland UI sys-
se Surveillance,

tifiers.³⁴⁰ These identifiers consist of four distinct components: (1) the last four digits of the Social Security number; (2) the numerical birth date (MM/DD/YY); and (3,4) numerical indications for a person's gender and race based on coding schemes used by the CDC.³⁴¹ The CDC has found that these systems are more costly to implement than named reporting and that their data contain a significant number of duplicate and difficult to match records.³⁴² UI systems are not as simple to operate as named-based reporting systems. The lack of simplicity, itself a flaw, is exasperated by the poor acceptance of the reporting method among medical providers and testing laboratories.³⁴³ Medical providers experience difficulty in correctly completing the UI form, due in part to difficulty in obtaining sufficient information from individuals. In 1996, health care providers in Texas and Maryland failed to provide a key element of the UI, the four digit component of an individual's Social Security number, in approximately twenty-two percent of the cases reported.³⁴⁴ Failures in supplying the Social Security component³⁴⁵ do not necessarily prevent medical workers from providing other UI components which are easier to determine. Still, a 1996 review of 20,000 case reports of HIV infection in Texas revealed that only

in Consultation on the Future Direction and Practice of HIV Infection and AIDS Case Surveillance in the United States (May 22, 1997) (on file with author).

³³⁹ See Centers for Disease Control and Prevention, *supra* note 338, at 1256 (describing the Texas UI system); Sharon Melville, *The Role of (Non-Name) Unique Identifiers in Case Surveillance*, in Consultation on the Future Direction and Practice of HIV Infection and AIDS Case Surveillance in the United States, sponsored by the CDC (May 22, 1997) (on file with author).

³⁴⁰ For a general overview of HIV reporting systems in Maryland and Texas, see Forbes, *supra* note 115, at 2-3 (noting that in Oregon some medical providers use unique identifiers for lab-based reporting of CD4 test results); and *Viable Alternative Article*, *supra* note 237, at 8 (reporting how the UI systems of both states work).

³⁴¹ See *Viable Alternative Article*, *supra* note 237, at 8 (explaining how the unique identifier is calculated). Thus, for example, the unique identifier for an African-American male born on January 1, 1960 whose Social Security number is 406-89-1234 is as follows: 1234-010160-21.

³⁴² See Centers for Disease Control and Prevention, *supra* note 338, at 1258-59.

³⁴³ See *Viable Alternative Article*, *supra* note 237, at 8-9 (noting that components were often left out of the identifier by the reporter).

³⁴⁴ See *id.* at 8. This rate, consistent between both states, however, represents a significant improvement over initial compliance in the first years of the states' UI programs. In its inaugural year, 33% of the reports in Maryland were missing the Social Security component. In Texas, the initial rate of missing components was 57%. See *id.*

³⁴⁵ Health care workers in Texas and Maryland report difficulty in getting patients to provide their Social Security numbers. See *id.* at 8-9. Some illegal immigrants do not have Social Security numbers. See *id.* As well, commercial testing labs in Texas have been reluctant to collect and provide Social Security numbers of those tested where such would require expensive reprogramming of computer database systems. See *id.*

forty-nine percent of the reports have all four UI elements.³⁴⁶ Over a two and a half year period, only seventy-one percent of the UI reports in Maryland and sixty-one percent of the reports in Texas, were fully completed.³⁴⁷

Pursuant to a three year collaborative study between Maryland, Texas, and the CDC, UI systems were evaluated for completeness, timeliness, and the ability to match UI records to individual patients and alternate public health databases.³⁴⁸ While both states fared well with the timeliness in which UI reports were submitted, the completeness of such reports was abysmal compared to relevant statistics for named-based AIDS and HIV reporting systems.³⁴⁹ The ability to match complete UI reports to individual patients and alternate databases, including AIDS databases was complicated by the lack of patient logs kept by providers in Texas,³⁵⁰ and the failure of many providers to keep such logs in Maryland.³⁵¹ These same findings make it difficult to link UIs to patients for the laudable purpose of providing follow-up public health information and services.³⁵² As a result of its evaluation, the CDC concluded that several problems with UI reporting systems, including "a high number of reports with incomplete codes (approximately 30-40%), low rates of completeness in reporting (approximately 25-50% complete), difficulty in conducting follow-up on specific cases, and the absence of behavioral risk data,"³⁵³ negatively impact "the performance of an HIV surveillance system."³⁵⁴ For these reasons, non-named unique identifiers fail to provide high quality, unduplicated HIV data at a reasonable cost.

Some AIDS advocates recognize that UI systems are presently inadequate for national surveillance. They argue, however, that UI

³⁴⁶ See *id.* at 8.

³⁴⁷ See J. Stan Lehman, Presentation at the Centers for Disease Control's Implementation of National HIV Surveillance Workshop (Oct. 7, 1997) (figures on file with author).

³⁴⁸ See Centers for Disease Control and Prevention, *supra* note 338, at 1255.

³⁴⁹ See *id.* at 1258. The percentage of reports with the full UI in Maryland over the three year period from July 1994 to December 1996 was 71.4%. In Texas, this percentage was 61.6%, not including almost 7000 records in which more than three UI elements were missing and thus excluded from consideration. See *id.* at 1256 tbl.1. These percentages fared poorly compared to average percentages of completeness for name-based AIDS reporting (85%) and name-based HIV reporting (74% to 97%). See *id.* at 1258.

³⁵⁰ See *id.* at 1256.

³⁵¹ See *id.* at 1255 (stating that only 44% of test providers contacted by the CDC in Maryland were actually maintaining proper patient logs).

³⁵² See *id.* at 1258.

³⁵³ Centers for Disease Control, *supra* note 172, at 2.

³⁵⁴ Centers for Disease Control and Prevention, *supra* note 338, at 1258.

systems h
improper
tems.³⁵⁵
they argue
encourage
fidential.
health ser
be provide
all contag
improved.

These an
by extant
complete
based syst
discourage
reliable mo
they shoul

Even so,
vide rich
risks to pr
health aut
natural his
sician and
accessed th
Maryland
logs of repo
tion about
of private h
rately main
Security vi
semination
ties where

³⁵⁵ See, e.g.,
have been unf
that increased
tems currently

³⁵⁶ See SAN
relatively new

³⁵⁷ See Amer
could contain

³⁵⁸ See Cent
as the UI compl
sons that could

nts.³⁴⁶ Over
of the UI re-
s in Texas,

1 Maryland,
completeness,
individual pa-
both states
submitted,
l to relevant
ems.³⁴⁹ The
ents and al-
aplicated by
and the fail-
d.³⁵¹ These
for the laud-
mation and
cluded that
ing "a high
ely 30-40%),
25-50% com-
ses, and the
he perform-
asons, non-
unduplicated
re presently
ver, that UI

Implementation
thor).
is.

d over the three
percentage was
ents were miss-
percentages fared
AIDS reporting

e CDC in Mary-

systems have been undermined by insufficient federal funding and improper and unfair comparisons to named based surveillance systems.³⁵⁵ As UI systems improve with further implementation,³⁵⁶ they argue their benefits will be realized. Individuals will be fully encouraged to be tested for HIV, assured that their results are confidential. As more persons are encouraged to be tested, more public health services including education, counseling, and treatment can be provided. Additionally, since UI systems could be used to report all contagious conditions, total public health surveillance will be improved.³⁵⁷

These arguments have considerable merit, but are not supported by extant empirical data. Data suggest that UIs do not provide complete and reliable surveillance information and that a named-based system (when accompanied by autonomous testing) does not discourage HIV testing. Nevertheless, if UI systems that provide reliable monitoring of the epidemic could be developed in the future, they should be seriously considered.

Even so, there are strong reasons to believe that UIs cannot provide rich surveillance data and that they actually create increased risks to privacy. UI surveillance complicates the ability of public health authorities to obtain complex data about risk behaviors and natural history, the type of information that is available from physician and patient interview, and medical record reviews currently accessed through a patient's name. Because UI systems as seen in Maryland rely on physicians and laboratories to keep individual logs of reported cases to cross-check for duplicates, private information about HIV-infected individuals is kept centrally by thousands of private health care providers. Each of these locations must separately maintain adequate security protections to prevent breaches. Security violations, even on a limited basis, can result in the dissemination of intensely private information within local communities where affected individuals may reside.³⁵⁸

³⁵⁵ See, e.g., SAN FRANCISCO AIDS FOUND., *supra* note 191, at 7 (listing ways UI systems have been unfairly judged); American Civil Liberties Union, *supra* note 119, at 10-11 (stating that increased funding is needed for UI systems, as they are preferable to name-based systems currently in use).

³⁵⁶ See SAN FRANCISCO AIDS FOUND., *supra* note 191, at 7 (noting that UI systems are relatively new and will improve over time).

³⁵⁷ See American Civil Liberties Union, *supra* note 119, at 10-11 (stating that UI systems could contain more complete epidemiological data).

³⁵⁸ See Centers for Disease Control and Prevention, *supra* note 338, at 1258 (noting that as the UI complicates collection efforts, it "increases the number of lists of HIV-infected persons that could be disclosed in a breach of confidentiality").

In addition, UIs do not necessarily protect one's anonymity. Identifying characteristics within a UI record allows for identification of supposedly "anonymous" individuals through matching techniques.³⁵⁹ Where records such as HIV reporting forms accumulate a number of identifying characteristics about infected individuals,³⁶⁰ the potential to match those records, if improperly disseminated, can be quite simple.³⁶¹ For these reasons, maintaining reportable health information securely at local and state health departments through named-based reporting may improve overall security.

CONCLUSION

The symposium on health care policy, for which this Article and a corresponding lecture were presented, focused on the question, "What lessons have we learned from the AIDS pandemic?" Concerning HIV/AIDS reporting, we have learned a great deal. A national reporting system based on an end-stage condition (although its pathogen can be detected much earlier) is insufficient under historical, epidemiological, medical, legal, and ethical perspectives.

National AIDS reporting was implemented at a time when epidemiologic knowledge about the epidemic was limited to end-stage disease. Since then, medical science has revealed the AIDS pathogen (HIV), developed testing methods for HIV infection, and discovered effective treatment prolonging life and reducing infectiousness. These developments have resulted in marked changes in the epidemiology of HIV/AIDS. AIDS deaths are falling. Yet, national HIV prevalence remains virtually unknown. Early HIV diagnosis and treatment are critical toward controlling the epidemic and improving the lives of individuals with the disease. Consistent with reporting practices of other infectious diseases, reporting at the earliest known stage of HIV disease is justifiable from the public health perspective. Our recommendation for a national system of

³⁵⁹ See Latanya Sweeney, Address at the National Committee on Vital and Health Statistics Meeting on Confidentiality (Jan. 28, 1998) (transcript available from National Committee on Vital and Health Statistics) (arguing that the more specific the identifying characteristics, the easier it is to match individuals with such information).

³⁶⁰ See The Standard Report Form Recommended by the CDC, Adult HIV/AIDS Confidential Case Report Form 50.42A (on file with *Albany Law Review*). The form accumulates information such as a person's age, date of birth, local residence, sex, race, medical provider, manner of infection, type of insurer, and other characteristics.

³⁶¹ See *id.*

named H
Counterv
are adequ
of privat
named-ba
ently pro
without a
Princip
alization
delays ou
and lives
the justif
practice i
AIDS epi.

anonymity.
or identifica-
h matching
forms accu-
affected indi-
properly dis-
maintaining
te health de-
e overall se-

Article and a
he question,
emic?" Con-
deal. A na-
on (although
at under his-
pectives.
ie when epi-
to end-stage
AIDS patho-
, and discov-
fectiousness.
s in the epi-
Yet, national
IV diagnosis
emic and im-
sistent with
orting at the
m the public
al system of

named HIV reporting is justified on several public health grounds. Countervailing social concerns about potential invasions of privacy are adequately addressed through privacy and security protections of private health information held by the government through named-based reporting. Unique identifier reporting systems presently produce insufficient reporting information at excessive costs, without alleviating privacy concerns.

Principal among these lessons from the AIDS epidemic is the realization that failing to implement national HIV reporting likely delays our ability to control the epidemic and improve the health and lives of thousands of infected and at-risk individuals. Where the justifications for national HIV reporting are compelling and the practice is respectful of individual privacy, working to control the AIDS epidemic through more effective surveillance is essential.

and Health Statis-
National Commit-
ifying characteris-

V/AIDS Confiden-
n accumulates in-
medical provider,