

# Diabetes, HIV, and the Boundaries of Public Health

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**Abstract** The control of infectious diseases has traditionally fallen to public health and the clinical care of chronic diseases to private medicine. In New York City, however, the Department of Health and Mental Hygiene (DOHMH) has recently sought to expand its responsibilities in the oversight and management of chronic-disease care. In December 2005, in an effort to control epidemic rates of diabetes, the DOHMH began implementing a bold new plan for increased disease surveillance through electronic, laboratory-based reporting of A1C test results (a robust measure of blood-sugar levels). The controversy A1C reporting produced was relatively contained, but when Dr. Thomas Frieden, New York City health commissioner, called for the state to begin tracking viral loads and drug resistance among patients with HIV, both the medical community and a wider public took notice and have started to grapple with the meaning of expanded surveillance. In the context of the past century of medical surveillance in America, we analyze the current debates, focusing first on diabetes and then HIV. We identify the points of contention that arise from the city's proposed blend of public health surveillance, disease management, and quality improvement and suggest an approach to balancing the measures' perils and promises.

The control of infectious diseases has traditionally fallen to public health and the clinical care of chronic diseases to private medicine (Frieden 2004). There has, however, never been a clear, consistent boundary between public health and medicine. Public health has, at times, assumed a duty to meet the needs of populations that have been inadequately served by the existing health care system. Debate about the duties and limits of public health have sporadically roiled the public health and medical communities over the course of the past century (Visel tear 1973). How

far should public health, as an agent of the state, reach into the clinical relationship? What are the appropriate bounds of public health?

In New York City, the health department has sought to answer these questions by seeking to expand its responsibilities in the oversight and management of chronic-disease care. As of 2003, diabetes had become one of the leading causes of death in the city and accounted for some twenty thousand hospitalizations (Bronza 2005). To control the epidemic, the New York City health department put forward a bold proposal for electronic, laboratory-based reporting of A1C test results, a robust measure of blood-sugar levels (*Obesity, Fitness, and Wellness Week* 2005; Santora 2005; New York City Department of Health and Mental Hygiene [DOHMH] 2005a: 3). On December 14, 2005, the eleven-member New York City Board of Health unanimously endorsed the health department's surveillance plan, moving the city to the vanguard of chronic-disease management.

Never had a city government initiated an ongoing, systematic surveillance of diabetes for an entire population (Stein 2005; DOHMH 2005a: 4; Brewin 2005; D. K. Berger, medical director, Diabetes Prevention and Control Program, DOHMH, personal communication, January 27, 2006; M. Saynisch, director of electronic reporting, Division of Epidemiology, DOHMH, personal communication, January 27, 2006). Results are currently being drawn from the major labs in the city, which represent approximately 90 percent of the A1C lab work done for patients, whether they receive only sporadic medical care or are in the regular care of a private physician, a private managed care plan, or a public program such as Medicaid or Medicare. Prior national and international governmental efforts to advance such initiatives have remained either voluntary or limited to key risk groups.<sup>1</sup> The controversy A1C reporting produced was relatively contained, but when Dr. Thomas Frieden, commissioner of the New York City DOHMH, called for the state to begin tracking viral loads and drug resistance among patients with HIV, both the medical community and a wider public took notice and have started to grapple with the meaning of expanded surveillance. Frieden anticipated resistance and, speaking of his broader objectives, predicted that "some doctors, health care facilities,

1. For examples of voluntary initiatives, see Spero, Kenet, and Porter (1998); Gudbjornsdottir et al. (2003); Piwernetz (2001); Belgian Diabetes Registry (n.d.); Finnish Diabetes Association (n.d.); James et al. (2004); MacLean et al. (2004); DOHMH (2005a: 3). For initiatives limited to key risk groups, see Desai et al. (2003); Saadine et al. (2002); Saydah (2004); Harwell et al. (2001); Miller, Safford, and Pogach (2004); Montiori et al. (2002); Acton et al. (2001); Juvenile Diabetes Research Foundation (2001); Thompson et al. (2005); Oregon Legislative Assembly (2001); State of Wyoming (2002).

and organizations will oppose increased monitoring of treatment efficacy” (Frieden et al. 2005: 2401).

Frieden knew that more than privacy was at stake. Indeed, in the case of both diabetes and HIV, it has not been epidemiological monitoring of the disease or patterns of care that have raised objections. City health officials envision the new surveillance as the foundation for a system of providing feedback to both physician and patient with a focus on improving access to and supervising the quality and consistency of clinical care for these diseases of public health significance (ibid.: 2399). Although health departments do administer clinical care programs for some populations and are responsible for quality assurance in various arenas, no health department has ever sought to exercise such thorough influence over care that it does not directly provide. In assuming this more assertive posture, the health department has raised concerns about the specter of undue intrusions into the clinical domain.

As we debate the responsibilities and limits of public health, it is important to look back and consider the range of services that health departments have offered as health care providers, taking stock of how health officials’ aspirations have been both frustrated and realized. In the context of the past century of medical surveillance in America, we analyze the current debates—focusing first on diabetes and then HIV—identifying the points of contention that arise from this blend of public health surveillance, disease management, and quality improvement.

### **Public Health Surveillance in Historical Perspective**

In 2005, the New York City Department of Health and Mental Hygiene was described in the press as “break[ing] new ground” (Caruso 2005b) in seeking to collect data about diseases that are “neither contagious nor caused by an environmental toxin” (Stein 2005). Responding to New York City’s proposal, one Los Angeles County public health official observed, “Some people are uncomfortable with public health departments expanding their scope beyond infectious diseases, but I would say we have to do it” (Caruso 2005a). The diabetes and HIV initiatives, however, do not herald an entirely new trend extending the scope of public health surveillance to chronic conditions (Stein 2005). Nor do they raise new concerns about the limits of surveillance or, indeed, the limits of public health.

The practice of public health surveillance is Janus-faced. As a tool for identifying and locating individuals with disease, surveillance can be a

precursor for intruding upon the privacy and liberty of individuals with disease or at risk of disease. Yet surveillance is also essential for identifying clusters, mapping the spread of disease, understanding patterns of contagion, and detecting lapses in hospital infection control. The identification of populations at particular risk of disease and death has often triggered the provision of ongoing services to those groups. Health clinics, vaccination programs, and milk stations are just a few of the examples of public health responses to the needs of vulnerable populations during the twentieth century. Health officials can act as licensed intruders, who enter infrequently into the spheres of home, business, and medical care; arrest contagion or contain hazards; and then withdraw. But they can also fill positive, nonconfrontational functions that are well integrated into the fabric of daily life. Indeed, the public has sometimes accepted, even demanded, that health departments assume roles akin to those of health care providers.

Since the late nineteenth century, disease surveillance has provided an opportunity to engage in case management or offer clinical or other services. For example, public health officials first initiated tuberculosis surveillance at a time when the illness represented a chronic infectious disease, eliciting strenuous objections from physicians who wanted to prevent health departments from interfering or intervening with their private patients. Health officials accommodated physician demands and, in exchange for access to data, were willing to allow doctors to mediate access to their patients. Although at that time it was limited primarily to poor patients reliant on clinic care, the city was able to create its own vast system of sanitary supervision, with public health nurses making one-quarter of a million visits to patient homes in 1910 alone (Billings 1912). To be sure, this network of surveillance could and did result in the involuntary isolation of tubercular patients whose disease was a threat to the community or who sought to avoid continual clinical monitoring. There is evidence that, as a consequence, some people sought to elude the reach of the health department (Abel 1997). A similar system of surveillance, in which health officials monitored the clinical care of patients over time and took on the management of those who lacked a private physician, was soon established for venereal diseases. Likewise, in the 1920s and 1930s, health departments, in partnership with volunteer organizations such as the Elks Club and the National Foundation for Infantile Paralysis (the March of Dimes), began tracking crippled children and congenital malformations for the purpose of identifying children in need of services (Fairchild et al. forthcoming).

In all of these instances, any punitive aspects of surveillance initiatives were by far outstripped by the ongoing care for which they allowed (*ibid.*). Although such surveillance systems could and often did provoke controversy, the debates were almost entirely between health professionals: patients were not engaged in them because both public health and medicine were highly authoritarian and paternalistic throughout the first half of the twentieth century. The patient was in the “caring custody” of the physician, and privacy was considered to be a right not of the patient but of “both physicians and patients” (Billings 1912: 12).<sup>2</sup>

Despite this early history, public health became increasingly divorced from clinical care (Brandt and Gardner 2000). In part, this was because of the rise of the hospital and health insurance plans. In large measure, however, it also represented a failure on the part of public health authorities to extend their vision to growing areas of need (Fee and Brown 2002). Health departments were reluctant to undertake surveillance for noninfectious or occupational diseases because these diseases did not seem to fit the intervention and treatment model that had been established in infectious-disease surveillance. For example, when state and local health departments began tracking cancers in the 1940s, such surveillance had the limited mission of developing incidence and prevalence data and therefore did not follow the clinical progress of patients over time (Reynolds 1993; Dorn 1949).

Medicine, however, did see the potential for surveillance to enhance patient care. From the 1920s to the 1950s, provider- and hospital-based tumor registries, for example, emphasized improvements in patient care (National Cancer Institute n.d.; Johnson 2005). A decade later, in the 1960s, health care quality assurance, or the assessment of medical records to determine the adequacy of medical care, began to become standard medical practice, inspired by industrial efforts to control and improve the quality of consumer products (Swift, Humphrey, and Gor 2000). It also developed roots in federal agencies responsible for health. Quality assurance conducted by professional standards review organizations (PSROs) was one of the hallmarks of the provision of health care services under Medicare and Medicaid (Egdahl and Gertman 1976). By the 1970s, quality assurance had become integral to the management of medical care. As it evolved, quality assurance began to serve as both a tool for reacting to or even anticipating untoward health care events and as a

2. The emphasis on physician rights and noninterference would persist and often be explicitly articulated. See Bowles (1920: 14) and Zimmer (1939: 229).

proactive technique for regulating and improving the delivery of medical care (Gilpatrick 1999). Such data culling has involved not only private entities and clinicians but also federal and state agencies, including public health departments, that have maintained a role in health care provision. This type of oversight should not be confused with adverse or sentinel health care events that remain reportable largely on an institutional, voluntary basis in which hospitals and physicians are typically shielded from exposure (University of California at San Francisco, Stanford University Evidence-Based Practice Center 2001).

Thus, the state, most broadly construed, began to monitor and supervise the care that it funded and directly provided. Health departments also began to regain footholds in clinical territory. In the 1970s, responding in part to profound alterations in the health care milieu after the advent of Medicare and Medicaid, public health agencies became responsible for administering clinical service programs. New York City health commissioner Lowell Bellin (1977) even expressed the belief that quality and cost control in the provision of health services generally would increasingly become one of health departments' most essential functions.

While state health departments, the federal government, and private entities have used surveillance in similar ways and even collaborated over the course of the twentieth century, the public has often regarded state action very differently from private initiatives. Resistance to state action became a hallmark of the period after the 1960s and 1970s, as powerful rights-based social movements joined the fray and began to champion individual control over clinical decision making. Although medicine was the primary target of social change, public health initiatives, too, were questioned by the public in ways that they had not been during the first half of the twentieth century. As with medicine, this was particularly true in situations in which public health seemed to seek to override the judgment of the individual about his or her behavior or medical treatment (Rothman 1991).

State immunization and birth defects registries, for example, have often been accompanied by some type of individual follow-up by public health agencies. In the case of immunization registries, this has typically taken the form of a mail or telephone reminder for parents regarding upcoming or overdue vaccinations. Birth defects surveillance, by the same token, has historically served as a gateway to educational, vocational, and medical services for disabled children. Both undertakings have been challenged over the course of the past thirty years. Based on concerns rooted in anti-paternalism, parents have been able to demand opt-in requirements for

inclusion in a number of state immunization registries (Texas Department of State Health Services 2003). Grounded in the interest of privacy and as a reaction against the American history of coercive eugenics, alarm about stigmatizing children likewise led some states to develop mechanisms for allowing parents to either prevent reporting or remove identifying information from congenital defects registries.<sup>3</sup> To be sure, in most instances parents welcomed the services to which health departments directed them. However, in instances in which the health department neither provided nor funded clinical care services or in which its role vis-à-vis private practitioners was unclear, its intervention could easily be viewed as crossing a bright line.

At the dawn of the twenty-first century, the boundary between public health and clinical medicine is being put to the test. In unfolding debates over diabetes and HIV surveillance, patients, their advocates, and concerned citizens—echoing the arguments made by opponents of immunization registries and birth defects reporting—have expressed concerns that the new surveillance is the first step on the road back to intrusive paternalism. Yet, as we have seen in this brief overview, health departments have been intimately involved in providing care to those they monitor. This history requires us to distinguish paternalism—in a pejorative sense of the state overriding the judgment of the individual about his or her own health care—from providing for people, protecting the public welfare, and caring for the most vulnerable populations in society. Under one set of circumstances, surveillance represents burdensome scrutiny and amounts to a denial of privacy and choice; under another, it holds the promise of enhancing the prospects of access to appropriate care and expressing a commitment to social justice, a central moral norm for public health (Beauchamp 1976).

### **The Diabetes Debate**

On July 13, 2005, with the fanfare of a new public health campaign, the New York City Department of Health and Mental Hygiene announced its proposal for electronic laboratory-based reporting of hemoglobin A1C tests for all city residents (Brewin 2005; Silver and Berger n.d.; DOHMH 2005c: 8). According to the health department, approximately two hundred thousand people who have diabetes in the city have not been diag-

3. For a thorough discussion of immunization and birth defects surveillance, see Fairchild et al. (forthcoming), chapters 6 and 7.

nosed. In New York State, 31 percent of confirmed diabetic patients in commercial managed care and 42 percent in Medicaid managed care have an A1C indicative of “poor control” (DOHMH 2005a). Of those with diagnosed diabetes, 90 percent were unaware of their A1C levels (Silver and Berger n.d.).<sup>4</sup> To Diana K. Berger, medical director of the city’s Diabetes Prevention and Control Program, this startling figure indicated that “Either doctors aren’t sharing that information with their patients, or they’re sharing it and their patients aren’t understanding it, or they’re sharing it and the patients forget” (Jones 2005). Racial disparities in diabetes were also clear. The rate of diabetes is twice as high in non-Hispanic blacks as it is in whites in both New York City and the United States as a whole (Cowie et al. 2006; Fang et al. 1995). A1C levels in the South Bronx are particularly high (Grant et al. 2004).

In justifying the new surveillance initiative, the health department underscored its legal mandate to prevent and control chronic as well as communicable disease, citing cancer, dementia, and congenital malformations registries as providing well-established precedents for diabetes surveillance (DOHMH 2005a: 2; Silver and Berger n.d.). For Frieden—who, since the beginning of his tenure as health commissioner in 2002, had sought to increase the capacity of the health department to gather, evaluate, and act on information on the leading causes of death through community health surveys, behavioral and risk factor surveys, and other existing data sources (T. Frieden, personal communication, March 6, 2006)—it was essential to adopt a lab-based reporting system in order to understand “for the first time . . . the scope of the problem” (Goldman 2005). Thus, diabetes surveillance was deemed essential for program planning and outcomes assessment, which would enable the targeting of resources and development of programs to help health institutions, providers, and patients to control diabetes more efficiently (DOHMH 2005a: 3).

More radically, the health department proposed to use its authority to contact both doctors and patients when A1C levels suggested the need to review the clinical picture, facilitate diagnosis, and even modify the course of treatment (Osterweil 2005). In the 1990s, Frieden had been responsible for—first in New York and then in India—a “powerful” disease-management system that followed tuberculosis patients from diagnosis to cure and involved directly observed therapy (T. Frieden, personal communication,

4. Thomas Frieden stated, “I can’t tell you what proportion of how many people are in poor control. Ninety percent don’t know themselves” (Goldman 2005). See also Osterweil (2005); Jones (2005); Urbina (2006).



March 6, 2006). But the proposal was not simply the brainchild of an unusually proactive public health professional lacking precedent beyond Frieden's experience in tuberculosis control. The move to address diabetes was also akin to a great many other measures taken within private health care delivery entities to systematize and improve chronic-disease management. Aware that his proposal could be viewed as an intrusion when undertaken by public health, Frieden carefully described the goal of the proposed diabetes system as serving to help physicians better manage their patients and "to empower patients with more information. It is not," he stressed, "to interpose the Health Department between the doctor and the patient, in fact just the opposite; it's meant to strengthen the doctors and their attempt to take care of the patients" (DOHMH 2005c: 6).

In principle, chronic disease-management programs primarily seek to promote and enable vigilance on the parts of both patients and providers, compelling the latter to implement what they theoretically already know and ensuring that the former learn and respond to what they should already have been taught, thus correcting for the failures of systems oriented toward acute care as opposed to prevention or health maintenance (Bodenheimer, Wagner, and Grumbach 2002: 1775). In the case of diabetes, disease management has two functions: one is to improve patient lifestyle (e.g., to encourage patients to eat healthily and mindfully of blood sugar, exercise, and minimize stress), and the other is to assure appropriate health care delivery (e.g., to make sure that patients have two hemoglobin A1C blood tests per year, self-monitor blood sugar daily, test blood pressure yearly, test cholesterol, get eye and foot exams, and undergo drug treatment).<sup>5</sup>

Clinical information systems, which are generally widely available and routinely used, play a key role in streamlining disease management (Bodenheimer, Wagner, and Grumbach 2002: 1776). After a patient is diagnosed with diabetes and is entered into a computerized registry, tests such as measuring A1C and cholesterol levels can accumulate thereafter in the patient's record. The registry can notify staff when data that is due to be entered is missing, alert them when recorded levels indicate poor diabetes control, and aggregate data to provide information about general population health and individual physicians' performances (Bodenheimer, Wagner, and Grumbach 2002: 1776). The Vermont Diabetes Information System (VDIS) study, on which the New York City health department

5. Data from the Web site of the American Diabetes Association at [www.diabetes.org](http://www.diabetes.org), cited by Beaulieu et al. (2003).

relied heavily in advancing its diabetes surveillance initiative, used such a model to create its successful diabetes-management initiative (MacLean et al. 2004: 533).

New York City seized upon the Vermont study because the bounds within which it achieved its impressive results were regional rather than institutional: it supported the work of 121 providers in fifty-five clinical practice settings (ibid.: 538). Indeed, the Vermont investigators were convinced that the successes of diabetes-management programs implemented “in staff-model managed care organizations with robust information systems,” which were already well documented, could be reproduced outside the managed care setting (ibid.: 533). Their effort evolved from a voluminous and growing literature that suggests that diabetes-management programs can keep the disease markedly more controlled in discrete populations (Montiori et al. 2002; Diabetes Control and Complications Trial Research Group 1993; U.K. Prospective Diabetes Study Group 1998; Thompson et al. 2005; Bodenheimer, Wagner, and Grumbach 2002: 1777–1778). Because the payoff is long term, insurance companies have not always been eager to invest in diabetes management. Medicaid and Medicare managed care plans, however, have leaped to implement such programs (Schmittiel et al. 2005; Beaulieu et al. 2003; Leatherman et al. 2003: 30; Mangione et al. 2006; Rittenhouse and Robinson 2006; Patric et al. 2006; Roohan et al. 2006).

New York City officials proposed to build on a well-established chronic disease-management model. Beginning with a Bronx-based pilot program, which it plans to roll out to the other boroughs, the city will communicate with providers about the implications of their patients’ A1C tests. The city will also develop its own capacities for helping patients gain self-management skills: the health department plans to pilot a program of diabetes and nutrition education provided by certified diabetes educators and nutritionists in conjunction with the city’s existing “Shape Up New York” free physical fitness program, sponsored by the Department of Parks and Recreation. The crux of the initiative, however, is surveillance and clinical intervention. In moving this arm of the initiative forward, health department officials received encouragement as they consulted with organizations such as the Centers for Disease Control and Prevention (CDC); major city hospitals; clinicians throughout the city, particularly those practicing in the South Bronx, where the population is poor and diabetes rates are high; and patients with experience with disease-management technologies. National leaders of the American Diabetes Association (ADA) were likewise quite receptive to the notion of surveillance when

they were consulted by health department officials. Nathaniel Clark, the ADA's vice president of clinical affairs, had helped to develop the Vermont diabetes registry (DOHMH 2005a: 3). He felt strongly that registry efforts were particularly crucial for patients on the margins of the health care system—patients who had no ongoing relationship with a doctor and only sporadic medical care. It was appropriate for health departments to take responsibility when physicians or clinical care plans, including Medicaid and Medicaid managed care, let patients fall through the cracks.

Citizens, however, raised questions about the limits of health department intervention. Its long leadership in infectious-disease control would make many citizens skeptical about its intentions in the chronic-disease arena in which it sought to monitor care that it was not necessarily providing. Thus, as the ADA reached out to its advocacy committee made up primarily of volunteers, profound privacy concerns surfaced. The ADA's executive committee was subsequently convinced that it could only support AIC surveillance if patients gave consent at the time of each blood draw (N. Clark, ADA, personal communication, February 6, 2006). Likewise, in response to press coverage, a few from the city's general public began to contact the health department asking for a patient opt-in provision (D. K. Berger, personal communication, January 27, 2006). Although the system might be identical to that used by their health care providers, patients did not regard the state with the same trust.

In response to initial concerns about stigma and discrimination (*ibid.*), Commissioner Frieden argued that the privacy protections for the registry would be stronger than those for communicable-disease reporting (DOHMH 2005c: 5).<sup>6</sup> The notice of intention to amend the health code stated that “stringent confidentiality requirements . . . would prevent the sharing of diabetes diagnoses with anyone other than the patient or the treating medical providers” (DOHMH 2005a). Confidentiality provisions would explicitly prohibit information sharing that might “make it more difficult for persons with diabetes to obtain or renew a driver's license, health insurance, life insurance, etc.” (*ibid.*: 3–4). Indeed, even patients themselves would not be able to authorize further disclosure of their registry data (Silver and Berger n.d.).

6. For other chronic and infectious conditions, such as congenital malformations, cancer, HIV, and tuberculosis, both New York City and New York State specify the conditions under which registry data may be released beyond the patient and his or her provider, and there are clear provisions for releasing data with patient consent (New York State Department of Health 2004, 2005a, 2006a). See also NY Pub. Health Law §§ 2780–2787 (Consol. 2007), “HIV and AIDS Related Information”; NY Pub. Health Law § 2221, title II (Consol. 2007), “Control”; DOHMH (2005b: 13–14).

Further, the department agreed to allow patients to opt out of the program. Although it was not clear in the early stages of the controversy what that would entail, Frieden assured those who had come to testify at a public hearing that “anyone who doesn’t want to participate doesn’t have to, and procedures for not participating will be . . . similar to a do not call type registry, through e-mail, letter, with the Web, calling 311; making it very easy for people who never want to be a part of this, not to be part of it if they have diabetes” (DOHMH 2005c: 5; see also Goldman 2005). As Diana Berger later emphasized, any communication related to diabetes care that patients receive directly should come from their provider, not from the health department. Physician trust is also key. The health department has no plans to penalize or publicly identify providers with poor track records for diabetes care (D. K. Berger, personal communication, October 23, 2006).

Slightly less than half of the ten individuals who offered oral testimony at the public hearing held on August 17, 2005 (some of whom were also represented among the forty written comments the department received) were mollified. It is, of course, difficult to know how representative those who come forward to testify are of the broader population. Nevertheless, it is crucial to understand how those most motivated sought to frame the debate. What is striking is that, without exception, those who objected to the new surveillance regime, most of whom were individuals unaffiliated with any advocacy organization, cited privacy concerns. A medical privacy attorney who explained that she, too, managed a chronic health condition, commented, “To me diabetes is a very private matter that would become a public matter” (DOHMH 2005c: 38).

It was not only that patients feared that the health department could not secure their records but also that the act of surveillance was itself stigmatizing (*ibid.*: 49; see also DOHMH 2005c: 52; Goldman 2005). The proposed incursion on privacy was unacceptable to opponents because diabetes posed no communicable risk. One private patient who testified against the proposal stressed “that as a diabetic I am not a threat to the City’s public health, nor do I wish to be treated as one” (DOHMH 2005c: 49). This view was echoed by the American Clinical Laboratory Association, which objected that the measure placed burdens on laboratories in the absence of a clear public health danger (P. M. Kazon, Alston and Bird LLP, letter on behalf of the American Clinical Laboratory Association, August 16, 2005). An attorney described as representing health care groups concerned with medical privacy argued, “This isn’t smallpox. The state, or the city in this case, does not have a compelling interest in the

health of an individual that overrides that individual's right to privacy" (Caruso 2005a; see also Osterweil 2005). Another individual likewise asked, "What gives New York City the right to take my private information from me without my consent and usurp it as their own? Do I pose a bioterrorist threat? No. Is there some type of infectious disease threat? No. Is there an imminent threat that I will harm someone else? No" (DOHMH 2005c: 38).

More profoundly, people feared that surveillance would enable the government to make decisions for them. One diabetic expressed his "desire as a private citizen to keep my personal medical information private between my physician and myself and nobody else" (ibid.: 49, 52). Diabetes registration could only open the door to a cascade of greater intrusions. "What is next?" one opponent asked. "Will New York City get the gynecological records of every woman and put the ones who don't use proper birth control on a registry too?" (ibid.: 40). She did not need or want the city to "babysit" for her (ibid.: 38). Likewise, one patient flatly rejected what he called a "Big Brother approach to diabetes management" (ibid.: 44). He shared the concerns of another who asked, "Are you going to demand what I can and can't eat?" (anonymous, e-mail in DOHMH's file of public responses, July 25, 2005). A city resident with diabetes summed up patient opposition when he told the health commissioner that "you're sure as hell not my doctor"; "my diabetes is well controlled without your unasked-for paternalistic assistance and oversight" (anonymous, letter in DOHMH's file of public responses, July 27, 2005). Twila Brase, a public health nurse who heads the Citizens' Council on Health Care, an ideologically libertarian "free-market health care policy organization" that played a key role in opposing mandatory immunization registries, birth defects surveillance, and a universal patient medical identifier in Minnesota (Brase 1998), commented that "It's a little creepy that it's being done so undercover—in the laboratories—where it's completely out of sight of the doctor-patient interaction" (Stein 2005). Diabetes, in short, should not be "managed by anyone other than the patient along with his or her health care team" (DOHMH 2005c: 45).

Some providers likewise found efforts to blur the boundaries of the patient-provider relationship alarming. Absent the need to protect others from harm, the proposed system was characterized as an unwarranted extension of public health authority into the domain of medicine (Caruso 2005a; P. M. Kazon, letter on behalf of the American Clinical Laboratory Association, August 16, 2005). The Association of American Physicians and Surgeons (AAPS), an organization opposed to the "evil" of government-

based or “socialized” medicine (AAPS 1991), objected to lab-based AIC reporting as a “blatant invasion of patient privacy that will cause many patients to avoid testing and treatment” (A. Schlafly, general council, AAPS, letter to DOHMH, August 17, 2005). According to the AAPS, the plan would replace “individualized medical care with population-based medicine for patients having one of our nation’s most significant chronic diseases” (ibid.). Ironically, the AAPS, as well as the American Clinical Laboratory Association, cited *Whalen v. Roe* (429 U.S. 589 [1977])—the landmark Supreme Court case in which surveillance was unanimously and forcefully upheld—to assert that the proposed blood sugar reporting system was unconstitutional (ibid.).<sup>7</sup>

In *Whalen*, patients and their doctors challenged a New York statute requiring physicians to report the names of patients who obtained prescriptions for drugs with the potential for abuse such as barbiturates, tranquilizers, or amphetamines. The U. S. Supreme Court unanimously upheld reporting as “a reasonable exercise of the state’s broad police powers” (ibid.). Although the Court did, indeed, recognize a zone of medical privacy, it rejected the notion that any chink in the armor of privacy would threaten the clinical relationship. Disclosure of private patient information not only to the state health agencies but also to doctors, hospital personnel, and insurance companies might be “unpleasant,” but it was “an essential part of modern medical practice” even when such “disclosure may reflect unfavorably on the character of the patient” (ibid.). Critically, the Court gave its imprimatur to surveillance more generally, citing venereal disease, child abuse, deadly weapons injuries, and fetal death reports, including abortion records, as “familiar examples” of legitimate public health reporting (ibid.).

Because of the threat of government interference, virtually all of those testifying against the proposed surveillance of diabetics advocated for opt-in or informed-consent procedures that would give individuals a choice up front about whether or not to participate. Opt-out provisions that left it up to the patient to take steps to remove his or her name from the registry,

7. To resist intrusions on the private realm, the American Clinical Laboratory Association turned for authority to the case of *Jacobson v. Massachusetts* (197 U.S. 11 [1905]), which upheld the right of the state to require mandatory vaccination. The Liberty Coalition, which included the Association of American Physicians and Surgeons, the New York Republican Liberty Caucus, the National Lawyer’s Guild, Private Citizen Inc., the California Consumer Health Care Council, and the U.S. Bill of Rights Foundation, cited the case of the *United States v. Westinghouse* (638 F. 2d 570 [1980]), in which a U.S. district court upheld the right of the National Institute of Occupational Safety and Health to gain access to the medical records of workers in order to assess potential risks to their health.

they maintained, were simply too difficult and failed to give individuals a meaningful choice (DOHMH 2005c: 42). A public-school principal in Harlem, speaking outside the context of the public hearing on the city's diabetes initiative, stressed that while she welcomed the surveillance program and the help it promised, it was essential to obtain patient consent: "There is enough privacy invasion already in our society" (Caruso 2005a; see also Caruso 2005b).

For advocates of diabetes surveillance, however, complete ascertainment of cases was essential and a program that had to obtain consent would not be effective. Eran Bellin, Montefiore Medical Center's director of outcomes analysis and decision support and son of the former New York City health commissioner who had written in favor of health department–based health-service quality improvement in 1977, was doubtless cognizant of the ways in which informed-consent requirements threatened to compromise the scientific validity of public health data (Tu et al. 2004; Jacobsen et al. 1999). Although the program was not designed for 100 percent ascertainment of all cases in the city, being limited to labs that were equipped to report cases electronically, Bellin challenged those who pressed for an opt-in approach, arguing that any such protocol would result in a "grossly inaccurate undercount" and was "tantamount to undoing the entire effort" (DOHMH 2005c: 25).

Although there certainly would be some cases in which surveillance and intervention would not produce patient improvements, the city stood to gain better disease management and improvements in the quality of care in the vast majority of instances, particularly for populations who would not yet have had access to this service at all. That diabetes control, in particular, has been identified as a priority area for quality improvement both in the United States and internationally was reflected in the roster of physicians who advocated for lab-based A1C reporting at the public hearing in August 2005 (Adams and Corrigan 2003; Institute of Medicine 2001; MacLean et al. 2004; Istanbul Commitment 1999). Maria Pitaro, the associate medical director for Union Health Center, who testified in favor of the proposal, described herself as being in charge of quality improvement at her institution. She stressed that "what you don't measure you can't improve" (DOHMH 2005c: 13).<sup>8</sup> Bellin underscored that the proposed initiative promised to replicate on a citywide basis the protocols that individual institutions had put into place to enable "our

8. See also comments of Nellie Boma, medical director of Morrisania (DOHMH 2005c: 15); Steven A. Safyer, chief medical officer, Montefiore Medical Center, letter, August 11, 2005.

quality improvement physicians to track patients across the system and across time" (*ibid.*: 20).

Patients who had experience with the Vermont system were also solicited to show their support for such efforts. None of the Vermont participants who offered comments on the New York proposal felt that their privacy had been violated; all expressed confidence in registry security (anonymous authors, letters in DOHMH's file of public responses, August 12, 14, 15, 2005). Further, they underscored the direct benefits offered by disease management. One patient enrolled in the Vermont Diabetes Information System argued that, because of registration, "I get letters from my doctor reminding me when to have my blood tests and helping me to decide what to do with the blood tests. This has been a very good service for me" (anonymous, letter in DOHMH's file of public responses, August 12, 2005). Another noted he had more than once been alerted when he had fallen behind in getting his A1C tests. "Thank goodness for this wonderful program," he wrote (anonymous, e-mail in DOHMH's file of public responses, August 15, 2005). It is important to underscore, however, that the Vermont patients were praising a voluntary, practice-based diabetes registry. Their data was never shared with the state health officials. They expressed confidence in a system in which both they and their providers had agreed to participate as part of a research protocol. Thus, it is hard to say what their support portends about the acceptability of state-based surveillance.

The vast majority of physicians, likewise, drew little distinction between public health and managed care surveillance of diabetes and did not enter the fray. In this instance, it was not simply the case that medical organizations were not drawn into discussions about the proposed initiative: they did not respond when it became public. The Medical Society of the State of New York (MSSNY), while noting the new regime, offered no comment on it (MSSNY 2005; Joseph 2005). The New York County Medical Society took no notice at the time.

The lack of physician involvement may be partially explained by the routine experience of third-party oversight with the rise of managed care. Whether they bristle at the requirements or not, doctors now view as unremarkable the need to seek prior approval for or review of some of their clinical decisions. Outside of the private sector, Medicaid and Medicare and other publicly funded health care programs have given birth to governmental agencies that have treated the kind of surveillance involved in quality assurance and improvement as central to the fulfillment of a fiduciary responsibility to taxpayers. Nonetheless, in historical perspec-



tive, clinician quiescence is remarkable given that doctors and their professional organizations have been among the most ardent opponents of public health reporting efforts for more than a century, particularly when it has involved any kind of interference with patients or their treatment. Historically, when physicians were prepared to yield care and oversight to health departments, it was typically with impoverished populations. It is not at all clear, then, whether physicians and their representatives would remain equally complacent if, for example, it was disease management for a disease that was not overwhelmingly viewed as a problem of poor, nonwhite populations.

### **From Diabetes to HIV**

The diabetes measure was approved with remarkably little public controversy and debate, and the health department yielded little ground. Officials have now made clear that patients will only be allowed to refuse interventions, such as letters alerting their physicians when tests are due or when A1C levels are too high. Critically, all data will be retained in the registry in identifiable form (D. K. Berger, personal communication, January 27, 2006). Discussion, however, did not come to a close. Indeed, it intensified in the wake of the measure's passage. The American Civil Liberties Union (ACLU)—which had been so involved in debates about surveillance and privacy spawned during the past two decades by the AIDS epidemic, the Health Insurance Portability and Accountability Act (HIPAA), and bioterrorism—had been unaware of the proposal and hence missed the opportunity to comment at the public hearing.<sup>9</sup> Its local affiliate has since begun to formulate plans for restraining the hand of public health (S. M. McGowan, ACLU, personal communication, March 9, 2006). The New York City Council (2006), as part of its deliberations over the health department's budget for fiscal year 2006–2007, expressed deep concerns about patient privacy, with some council members pressing for informed consent.

In part, the diabetes controversy was stoked by a rapidly heating debate over a subsequent city proposal to routinize HIV testing and create a simi-

9. In part, this was a consequence of the health department's failure to reach out to those centrally concerned about privacy in the process of consultation. But it was also the case that both the New York City and national offices of the American Civil Liberties Union (ACLU) lacked staff focused specifically on medical privacy. Likewise, the groups who had engaged in the debates about HIV surveillance were not necessarily attuned to medical privacy more generally (J. Goldman, Health Privacy Project, personal communication, January 31, 2006).

lar system of lab-based reporting for HIV viral loads and drug resistance. Indeed, it was in the midst of the effort to mandate lab-based diabetes surveillance that the New York City DOHMH revealed the discovery of a particularly virulent, drug-resistant strain of HIV. In February 2005, Commissioner Frieden announced that the department had identified a single individual who had rapidly progressed to full-blown AIDS within only twenty months of infection; the case was resistant to three classes of antiretroviral drugs despite never having been treated. Perhaps because the scientific community became roiled in debate about the wisdom or necessity of a public announcement based on a single case, Frieden's call for the state health department to expand the scope of HIV surveillance by tracking viral load results as well as drug resistance initially drew little public attention (Santora and Altman 2005; Altman and Santora 2005; Altman 2005; MSSNY 2005; Joseph 2005).

The changes were justified by developments in testing techniques for lymphocyte and viral-load monitoring. The context was one in which remarkable strides in antiretroviral therapy since the mid-1990s had transformed a diagnosis of HIV from a death sentence into a problem necessitating chronic-disease management (Gostin, Ward, and Baker 1997). Combined with clinical presentation and other tests, newly available diagnostic tools provided a much more detailed picture of disease progression and prognosis (U.S. Food and Drug Administration 2005). Elevated viral levels or increased immune activity in the face of a particular antiretroviral therapy, for instance, could indicate a drug-resistant strain of HIV, lack of adherence to a treatment regimen, decreased absorption of drugs, physiological changes affecting drug metabolism, drug interactions, the impact of vaccinations, or the presence of other infections (Schalla et al. 2001: 9).

Leaps had also been made in the realm of rapid HIV testing: in November 2002, the FDA approved the OraQuick HIV rapid test, which "provides results in 20 minutes, can be stored at room temperature, requires no special equipment, and can be performed outside clinical settings" (Janssen et al. 2003: 330). When the New York State Department of Health sent out its "2005 Guidance for HIV Counseling and Testing and New Laboratory Reporting Requirements," bearing the news of the emergency regulatory amendments regarding laboratory surveillance, it cited the OraQuick technology in justifying its expanded efforts. Rapid tests were a key reason, the state maintained, for "extending the reach of HIV testing" (New York State Department of Health 2005c). Not only did the CDC recommend making rapid testing more widely available, but it also

made clear that it would be revising its HIV testing guidelines and would soon recommend routine testing for the entire population, not just for specific risk groups (Branson et al. 2006). In a parallel move, Commissioner Frieden initially coupled his proposal for expanded surveillance with an ardent effort to eliminate New York's pretest counseling requirement along with written informed consent for the test.

The two prongs of Frieden's proposal—making HIV testing routine within the course of primary care and continuing to track viral loads once testing identified people with infection—each presented its own promise of benefit and basis for provocation. The support and opposition for the reporting initiative would reflect the long-standing debate about the appropriate uses of surveillance data in the context of the AIDS epidemic (Fairchild et al. forthcoming) and would expose in new ways divisions of race and class among those concerned.

On the surface, there was concordance between the city and the state on the surveillance initiative. In response to the changing clinical context, the state began requiring laboratories to report detectable HIV viral-load levels in 2000 (G. Birkhead, New York State Department of Health, AIDS Institute, e-mail to A. Fairchild, February 2, 2006). The city's alert about the multidrug-resistant strain of HIV prompted the New York State Department of Health to require laboratories to report undetectable viral load results and antiviral drug resistance under emergency regulations, which in 2006 were being prepared for publication and public comment (New York State Department of Health 2005b). "As persons with HIV/AIDS live longer," noted the state in expressing its intent to modify reporting procedures, "the authorized exchange of medical information is increasingly beneficial for coordination of medical care and other HIV-related services" (ibid.: 16).

If, however, the state felt it was urgent to gain access to and exchange a broader array of data between public health and medicine, its intentions when it came to using the data could not have been more different from the city's. It was "population-based data" on the "extent of resistance" that the state sought: "*aggregate* data will be extremely valuable to physicians, providing them with information on the resistance patterns that will help guide HIV treatment practices" (ibid.: 17). While the state felt that it was critical to establish an "early warning system" for drug resistance with a particular focus on new cases (ibid.: 18), data could be used for epidemiological purposes only (G. Birkhead, e-mail, February 2, 2006; Santora 2006a).

Frieden, in sharp contrast, sought to use surveillance as a wedge for

direct intervention—monitoring trends in the epidemic and program planning would not be enough. A year after bringing the drug-resistant strain of HIV to public attention, Frieden framed his initiative as an effort to reach the most vulnerable individuals in the city, telling a *New York Times* reporter, “We know people are dying, and we are prohibited by law from lifting a finger to try and help” (Santora 2006a) in the same fashion that “we are able to do . . . with every other communicable disease” (DOHMH 2006b; see also DOHMH 2006a; Osborne 2006). Of chief concern were patients lost to care, who had “no one responsible, no one accountable” for their medical management (T. Frieden, personal communication, March 6, 2006). “If you’re black in New York,” said Frieden, “you’re three times more likely to have HIV and six times more likely to die from it. Not only is there a disparity in infection rates, but among those infected there’s a huge disparity in outcome” (Osborne 2006; see also Santora 2006b). These figures, said Frieden, represent “a damning indictment of our system” (Santora 2006a). Frieden meant not only to use epidemiological data to target testing and outreach but also to intervene when drug-resistant cases emerged and to work at preventing such strains by improving the care that diagnosed patients received more generally.

Some within the state took Frieden at his word, viewing the measure as an unwelcome critique of well-established programs (New York State Department of Health AIDS Institute, memorandum of concerns regarding proposals to extend surveillance and intervention, n.d.). The New York State Department of Health’s AIDS Institute provides access to free health care to HIV-positive individuals through four programs: the AIDS Drug Assistance Program (ADAP) provides free medications; ADAP Plus provides primary care at a number of clinics, hospitals, and doctors’ offices; the HIV Home Care Program provides home care; and the ADAP Plus Continuation Program (APIC) provides payments to commercial health insurance plans on behalf of those who have lost their coverage because of inability to pay or losing a job (New York State Department of Health 2006b). What could the city offer over and above these programs, which also include a well-established case-management system?

What the city proposed was a “comprehensive approach to improve prevention, diagnosis, treatment, case management, and epidemic control” (DOHMH 2006a). The health department circulated a bill among state legislators that explicitly sought “to enable local public health officials to use available information, or receive additional information, as necessary, to facilitate optimal care and linkages for HIV-positive persons and their partners” (DOHMH n.d.b: 1, 3). Thus, the bill would have

allowed health officers to access all information on a patient's history of antiretroviral treatment from health providers and facilities (DOHMH n.d.a: 1). It would, in addition, permit health officials to contact and share information with both the treating physician—"only after validation that the physician is the provider of HIV care"—and the patient (DOHMH 2006c). For example, explained Frieden, when health officials become aware of a patient whose health is in danger unless treatment is modified, the city should be able to use the information already in hand and contact the patient and consult with his or her provider (Santora 2006a; Osborne 2006; Straube 2006; DOHMH 2006b). The health department argued that it was uniquely positioned to refer newly diagnosed cases to care, contact patients directly if necessary, and help physicians locate patients who dropped out of care (T. Frieden, personal communication, March 6, 2006; DOHMH 2006c).

A *New York Times* editorial (2006) gave a resounding endorsement to the city's proposals. Underscoring the ways in which surveillance could be viewed as a protection rather than as a threatening intrusion, the *Times* argued that "surely most patients would rather get life-extending treatments than languish in neglect." The Latino Commission on AIDS (2006) was similarly supportive, viewing expanded monitoring as representing a "third pair of eyes" that promised to benefit minority patients in New York City. The health department impanelled a twenty-one-member commission on HIV/AIDS to make recommendations on prevention, treatment, and care. This commission, which included representatives from such diverse organizations as the National Black Leadership Coalition on AIDS, Harlem Director's Group, Medius Institute for Gay Men's Health, and Gay Men's Health Crisis, endorsed proposed changes in laboratory reporting to the state and city. It stopped short, however, of recommending the use of such data on a "patient-specific basis" in the absence of further evaluation (New York City Commission on HIV/AIDS 2005: 29, 35).

Those skeptical of the plan attempted to separate the issues that were merged in Frieden's concept of the health department's role. Epidemiological monitoring of trends in the spread of disease, quality of care, and access to care were essential; direct supervision of infected individuals or their doctors was both unnecessary and unacceptable. Ronald Johnson of the Gay Men's Health Crisis also underscored issues of access that characterized the minority experience with the health care system when he commented that the issue for African American gay men is not that of falling through the cracks once they receive care but that of even getting into the system for an initial test (Straube 2006). For other groups, opposition

was grounded in arguments about limited resources. The AIDS Coalition to Unleash Power (ACT UP) questioned the financial logic behind investing in individual disease management, grounding its opposition in the diversion of “scarce resources from effective HIV prevention efforts” (M. K. Swirsky, ACT UP, letter concerning May 19, 2005, draft report by New York City Commission on HIV/AIDS, June 10, 2005). Likewise, the New York AIDS Coalition (2005a)—an alliance of community-based organizations—and, indeed, some within the New York State Department of Health’s AIDS Institute questioned whether these efforts would merely duplicate the existing case-management system (New York AIDS Coalition 2005b; New York State Department of Health AIDS Institute, memorandum of concerns regarding proposals to extend surveillance and intervention, n.d.). Others, however, downplayed issues of race, class, or resources. Housing Works, another AIDS advocacy group that framed its opposition in broader philosophical terms, asserted that “the very fact that lab work is being done demonstrates that the patient is already in the care of a healthcare provider licensed by the State of New York” (Cordero 2006).

Worries about paternalism continued to remain central. The public policy director for Housing Works—which emerged as the foremost opponent in the attack on the new surveillance—expressed concern about health officials making contact with a patient’s health care provider without consent or perhaps second-guessing the doctor (Santora 2006a; *New York Times* 2006). Testifying before the U.S. Presidential Advisory Council on HIV/AIDS, Housing Works, in language that echoed the opposition to the diabetes surveillance initiative, spoke out against the city plan “to interfere in the doctor-patient relationship of people living with HIV/AIDS” (Housing Works 2006). Said one of the group’s community organizers, “Receiving a call from an unknown bureaucrat questioning the quality of my care and the decisions that my doctor and I are making about my treatment” represents nothing more than “Big Brother watching over our shoulder” (ibid.; see also Cordero 2006; New York AIDS Coalition 2005b).

As was true in the response to proposals for diabetes surveillance, some activists feared a slippery slope of intervention and saw the potential for expanded surveillance to take on far more coercive dimensions. “How this information could be used to sanction patients or clinical providers who don’t comply with the wishes of public health officials is a serious question that must be explored,” insisted the New York AIDS Coalition (2005b).

“Perhaps in the beginning the intrusion will only be advisory. But who knows what future use of this power of intrusion might be put to,” cautioned one advocate. “Am I going to be coerced into treatment, or sanctioned for being non-adherent?” (Housing Works 2006). ACT UP expressed similar concerns, although without the bristling anger that characterized its response to surveillance in earlier periods: “We question the . . . coercive, even if ostensibly benign, state interventions to control the epidemic” (M. Swirsky, letter, May 19, 2005). Although activists recognized that government had become more willing and able to support persons with AIDS in its efforts to stem the spread of the disease, they vividly remembered a time not long ago when being identified to authorities as HIV positive brought only the threat of exposure and stigmatization and no promise of protection or assistance. They remained hesitant to sanction Frieden’s assertion that only public health oversight could create the synergy necessary for officials to meet need where it was greatest and avert future crises of contagion.

In response to concerns about paternalism and coercion, the health department expressed a commitment to use a consent or opt-in model for the purposes of using surveillance data to link individuals to care (DOHMH n.d.a, n.d.b). As in the case of diabetes, individual data would remain part of the registry. Although the details about how consent would be implemented remained unclear at a juncture at which health officials continued to modify the bill prior to ultimately withdrawing it, an opt-in model seemed likely. In other words, it appeared that individuals would not be included in disease-management efforts until they agreed—as opposed to the situation in diabetes where they would be required to take the initiative on their own, perhaps only after they had been subject to the intervention.

In addition, the health department was compelled to treat the issue of direct patient intervention with special care. In a letter to community members, Commissioner Frieden explained, “We would reach out to treating doctors, case managers and, *only if there are no viable alternatives*, directly to patients to offer to help link them to existing HIV services” (T. Frieden, letter to community, March 6, 2006; emphasis in original). Although taking a softer stance on direct intervention, Frieden nonetheless continued to underscore the imperative for change, arguing that “the epidemic demands new and effective approaches to reach patients who are not in care” (ibid.).

As the city anticipated the September 2006 release of the new CDC guidelines that would recommend routine HIV testing and as leading

ethicists in the region described the surveillance plan as “half baked,”<sup>10</sup> the city health department made a strategic decision to retreat from an expanded surveillance system. It chose to focus its efforts instead on eliminating written informed consent for HIV testing, but even here it faced resistance. The New York State legislature has proved reluctant to reconsider its nearly ten-year-old, exacting informed-consent law. Given the progress already made in diabetes surveillance, however, the question of expanded, more vigorous HIV surveillance will certainly recur. Indeed, Commissioner Frieden has suggested other areas, such as colon cancer, in which we might see future efforts on the part of public health to contribute to clinical care (Frieden 2004). The prospect of joining public health surveillance with disease management and quality improvement for a chronic condition demands that we confront old questions about the appropriate bounds of public health in the context of a transformed but still profoundly fragmented health care delivery system.

### **Conclusion: Beyond Privacy, Beyond Surveillance**

The recent politics of disease surveillance in New York City help to illuminate when and under what circumstances disease surveillance can break free of a historical division between public health and medicine. The irony is that the city made headway not with infectious diseases, an area in which it has traditionally enjoyed greatest authority, but with chronic diseases. The diabetes measure moved forward whereas a virtually identical proposal for the most significant infectious threat faced by the city was, at least for the time being, tabled in order to pursue the pressing policy priority of routinizing HIV testing. In both instances, the disease-management systems for which the health department advocated already existed in both private- and public-sector health care. In both instances, opponents of public health surveillance feared the slippery slope of government interference. In the instance of HIV, however, those fears held more traction. A better-organized community, with a long memory of threats of coercion involving those harboring the infection, effectively thwarted more aggressive surveillance.

10. A sentiment expressed at “HIV Testing and Surveillance: Time for a Change?” a meeting funded by the American Foundation for AIDS Research and sponsored by the Center for the History and Ethics of Public Health in the Department of Sociomedical Sciences, Columbia University, Mailman School of Public Health, May 2, 2006.



In both instances, the specter of a malignant paternalism was raised. In the HIV debates, the specter of paternalism invited concerns about undue intrusions in the lives of those made vulnerable not only by disease but also by race and class and has threatened to obscure the fact that the new measures are far less about deciding for people and far more about providing for them. Indeed, it was the unmet need of marginalized populations that called forth the public health effort to fill a yawning gap.

As we have shown, private actors—particularly in the field of diabetes care—have already crossed the surveillance threshold and challenged the dyadic doctor-patient model of care without raising the specter of “Big Brother in his civilian clothes” (Brenton 1964: 12; see also p. 13).<sup>11</sup> In large measure this is because a patient’s providers have agreed to this kind of supervision by participating in different insurance or managed care plans. Health officials, then, face the unique challenges of acknowledging the threat that state-based surveillance poses and specifying how it will limit government interventions while also making the case for the potential promise of public health oversight and intervention.

There is ample evidence that access to health care has a significant impact on successful diabetes control (Orr and Boyages 2005). The ability of quality improvement and case-management efforts to reduce racial disparities in A1C levels—a tall and complicated order—has yet to be demonstrated (Sequist et al. 2006). Thus, it remains to be seen whether the city health department’s efforts at diabetes surveillance will be effective in overcoming the existing barriers to health care, particularly in low-income areas such as the South Bronx. Likewise, if the city’s thwarted system of HIV surveillance is able to overcome political obstacles, it will confront similar implementation barriers.

We should not measure the impact of diabetes, HIV, or any chronic-disease surveillance effort only in empirical terms, however. The most difficult question regards a moral and political decision about the role and responsibility of public health. Mirroring the debates that have taken place within public health since the 1930s,<sup>12</sup> some in public health question not only whether health officials can successfully take on the challenge of clinical disease management but also whether they should (New York AIDS Coalition 2005b; New York State Department of Health AIDS Institute, memorandum of concerns regarding proposals to extend surveil-

11. Brenton made this charge during a period of increased popular anxiety about both government surveillance and unauthorized commercial surveillance.

12. See, for example, Brandt and Gardner (2000); Fee (1987: 227–236); Colgrove (forthcoming); Fairchild et al. (forthcoming).

lance and intervention, n.d.). At stake is not just a new model of chronic-disease surveillance in which it is necessary to balance individual privacy and autonomy against the greater good but also the recurrence of a persistent question about the mandate of public health.

Even if it cannot eliminate racial disparities in chronic diseases to the extent that it becomes a force for improving access to health care, public health serves the larger end of social justice. Even in the absence of a disease-management component, truly comprehensive public health surveillance could reveal not only the shortcomings of individual doctors but also much larger ethnic and class disparities that are symptomatic of our highly segmented health care delivery system. To the extent that private or publicly funded programs like Medicaid and Medicare managed care do not fulfill their mission, surveillance represents both a source of epidemiological data and a kind of social vigilance keeping our failures on the political radar. Even if it cannot correct the failures in our health care system, extending public health surveillance to chronic diseases represents an important step in the realization of social justice. Commercial interests have already begun to make the most of surveillance data, although largely because of cost savings. If public health is to advance its “historic dream . . . of social justice” (Beauchamp 1976: 6), it is time to take a step back and look ahead.

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