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# The Right to Know, The Right to be Counted, The Right to Resist: Cancer, AIDS, and the Politics of Privacy and Surveillance in Post-War America

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## Abstract

*The practice of public health begins with surveillance, the identification of individuals with disease. But while not all efforts to monitor morbidity and mortality entail formal notification of individual cases, the name-based reporting of individuals always involves a breach of privacy. The pitched battles over surveillance that marked the first two decades of the AIDS epidemic and, indeed, more recent global debates over the reach of the surveillance state in the name of national security might suggest a kind of timeless, furious battle on the part of those who would be subject to surveillance to defend a 'right to be left alone.' But just as often, indeed, perhaps more often, citizens have claimed a right to be counted, demanding surveillance in the face of unknown health threats. In either case, however, in the United States, regardless of whether communities pushed for or against disease reporting, marked citizen engagement has shaped the politics of surveillance since the 1970s. To be sure, privacy was always at stake. But so, too, were what activists conceived of as the right to be counted and the right to know.*

## Introduction

Surveillance is the radar of public health.<sup>1</sup> The collection of personal data, often identified by name, provides the foundation for understanding broad patterns of disease and planning for intervention. The Ebola crisis dramatically underscored the potentially devastating consequences of countries lacking the capacity to monitor the incidence and spread of disease: if officials do not know who is infected, they cannot isolate cases, they cannot track contacts, and they cannot quarantine those who might fuel an epidemic.

In the early months of the Ebola epidemic, international health officials painted a stark picture of undercounting. The World Health Organization (WHO) estimated in Fall 2014 that there were at least 2.5 times more infections

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<sup>1</sup> Amy L. Fairchild, Ronald Bayer & James Colgrove, *Searching Eyes: Privacy, the State and Disease Surveillance in America* (Berkeley, CA: University of California Press 2007).

than were being reported. Underestimates were due not solely to limited personnel, but also to the lack of a basic infrastructure for reliable disease reporting. The 'bad data' pendulum then swung in other direction. Inflated estimates of both the spread of the epidemic and associated mortality rates, some argue, fueled a social epidemic – one of panic – driving people away from care, leading to unnecessary military lock-downs, and inspiring overreaching Western quarantine protocols (New York State and New Jersey in the U.S. were paradigmatic examples) that threatened to impede the flow of resources and volunteers. Concluded the *New York Times*, 'Valid, credible and timely data is essential during a global crisis. Without reliable data, efforts to assist affected people and to rebuild damaged communities can be misdirected and inefficient.'<sup>2</sup>

But if Ebola illuminates the dual consequences of gaps in surveillance, current events in the major industrialized nations throw a spotlight on unrestrained surveillance. At a time of growing anxiety about national security surveillance and, indeed, commercial surveillance, the importance of protecting the integrity of public health data collection, use, and dissemination requires renewed, sustained attention. It is a challenge to determine whether global populations should be more alarmed by the 'prying eyes' of the likes of the U.S. National Security Agency or by multinational companies like Walmart that track our every purchase to predict our desires. Such 'big data' marketing efforts may not feel as dramatic as covert government surveillance but they are potentially as consequential for, say, the teenaged girl whose parents see that she is being targeted with ads for pregnant women.

Much of our current understanding of surveillance emphasizes this second, ominous narrative. And, indeed, the late nineteenth and early twentieth centuries, as officials moved to develop a surveillance regime over chronic infectious disease, were punctuated by furious and extended conflicts between doctors and health officials over the imposition of reporting requirements for tuberculosis and venereal diseases: doctors opposed surveillance in the name of patient privacy. The public health response to these conflicts was to accommodate physician sensibilities regarding the limits of public health in the private lives of their patients and, indeed, their sphere of clinical authority. But what was perhaps more interesting about the early battles over surveillance is that they were purely professional: the public was completely unengaged at a moment when both public health and medicine were highly authoritarian and paternalistic. It was an era of 'paternalistic privacy,'<sup>3</sup> in which privacy emerged as not so much a right of the patient, but rather as a feature of the clinical relationship. It was the doctor who controlled the terms of privacy in an instrumental way,

<sup>2</sup> Rachel Glennerster, Herbert M'Leod & Tavnet Suri, 'How Bad Data Fed the Ebola Epidemic', *New York Times*, January 30, 2015.

<sup>3</sup> Amy L. Fairchild, Ronald Bayer & James Colgrove, *Searching Eyes: Privacy, the State and Disease Surveillance in America* (Berkeley, CA: University of California Press 2007).

that is, in a fashion that contributed to good medicine (and that protected medical authority).<sup>4</sup>

By the late 1960s, patients' rights, feminist, and consumer activist movements all galvanized challenges to medical paternalism and physician authority.<sup>5</sup> As one historian observed, 'The rules for patients had changed: docile obedience was to give way to wary consumerism.'<sup>6</sup> The forces that gave birth to such changes provided the context for and were in turn energized by the new bioethics, which had as its lodestar a commitment to patient self-determination and a rejection of medical paternalism. The cultural embrace of an invigorated conception of privacy and the emergence of the patients' rights movement would ultimately set the stage for a constitutional challenge to surveillance by public health departments in the 1977 case of *Whalen v. Roe*. In this first – and still only – public health surveillance case considered by the U.S. Supreme Court, the tribunal turned back a challenge to the constitutionality of such efforts. Indeed, it gave its imprimatur to a wide range of public health surveillance efforts. But the politics of surveillance would not be so easily resolved. In the last decades of the twentieth century, the potential subjects of surveillance moved beyond the status of plaintiffs to become active participants in the process of policy making, empowered by a new democratic ethos.

But while dramatic resistance often marked the era of democratic privacy to disease surveillance, it would be a mistake to understand democratic engagement in the politics of public health as uniformly hostile to the practice of name-based notification. Likewise it would be a mistake to imagine that privacy was always prioritized. In some instances, privacy had what Robert McCloskey called 'the smell of the lamp about it': while it was central to an open, democratic society, day in and day out a right like privacy might better reflect the values of intellectual or political elite 'rather than the real preferences of the commonality of mortals.'<sup>7</sup> Often, it was complacency and silence that advocates resisted. More mundane or 'normative' rights that perhaps more profoundly shape daily experience<sup>8</sup> – the right to know and the right to be counted – thus emerged to support the claims for surveillance.

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4 Carl F. Ameringer, *State Medical Boards and the Politics of Public Protection* (Baltimore: Johns Hopkins University Press 1999), 22-23, 25; John A. Harrington, 'The instrumental uses of autonomy: a review of AIDS law and policy in Europe', *Social Science & Medicine* 55:8 (October 2002), 1425-34.

5 Nancy Tomes, in: Rosemary A. Stevens, Charles E. Rosenberg & Lawton R. Burns (eds.), *Health Care History and Policy in the United States* (New Brunswick, NJ: Rutgers University Press 2006).

6 David J. Rothman, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision-Making* (New York: Basic Books 1991), 144.

7 Robert McCloskey, 'Economic Due Process and the Supreme Court: An Exhumation and Reburial', *Supreme Court Review* (1962), 34, 46.

8 Janet E. Frantz, 'Political Resources for Policy Terminators', *Policy Studies Journal* 30 (2002), 24.

This paper first examines the battles over cancer registration beginning in the 1970s, which illuminate the expanding patient role in the politics of public health by exploring an instance in which the public demanded both the 'right to be counted' and the 'right to know' and rejected privacy as a value that trumped all others. The story would be very different with the AIDS epidemic. When health departments began to consider HIV reporting, the politics of democratic privacy became full-blown, erupting into an extraordinary two-decade battle over the nature and extent of disease surveillance as communities affected by AIDS resisted surveillance efforts.

### **Cancer: The Right to Be Counted, The Right to Know**

By the 1920s, after a series of battles over tuberculosis and venereal disease notification that often resulted in a compromise in which the privacy of private patients was preserved while the names of the poor went to health officials, surveillance had become a core feature of what public health departments believed was essential to their work. Hence there emerged a new emphasis on the importance of reporting for all diseases.<sup>9</sup> In most instances, there was no question that diseases would be reported by name, though coded reporting exceptions for venereal diseases persisted, in some states to this day.

But even as surveillance for both chronic infectious and communicable diseases became widely accepted, an epidemiological transition occurred. Such infections declined with clean water provision and waste removal that went hand in hand with fundamental changes in land use, housing, transportation. But new hazards gave rise to new diseases. Cancers and other chronic conditions became the paradigmatic conditions that plagued those in the twentieth century.<sup>10</sup> Cancer would pose a challenge to the paradigm of surveillance. Hence, after an initial period of enthusiasm for routine surveillance of cancer incidence in the 1910s and 1920s, the idea of universal reporting along the lines of infectious disease notification dropped off the radar.<sup>11</sup> Cancer presented a conundrum to the public health profession, which at the time was highly oriented toward

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<sup>9</sup> *Northwest Medical Journal* XVII. 1918. Importance of Communicable Disease Reports; *Illinois Medical Journal* 19. 1911. Public Health; *American Journal of Public Health*. 1919. What Diseases Should Be Reported. Vol. 9, no. 6 (June): 451.

<sup>10</sup> Amy L. Fairchild, David Rosner, James Colgrove, Ronald Bayer & Linda Fried, 'The Exodus of Public Health: What History Can Tell Us about Its Future', *American Journal of Public Health* 100 (2012), no. 1 (January): 54-63, <http://ajph.aphapublications.org/cgi/content/short/100/1/54> (accessed March 11, 2010).

<sup>11</sup> Victor A. Triolo & Michael B. Shimkin, 'The American Cancer Society and Cancer Research Origins an Organization: 1913-1943', *Cancer Research* 29:9 (September 1969), 1615-1640.

laboratory techniques aimed at identifying specific disease-causing germs.<sup>12</sup> The American Public Health Association was resigned to the fact that the condition could not be prevented or controlled with the same techniques that had been applied to contagious threats. While surveillance of tuberculosis or venereal diseases had presented numerous logistical difficulties, at least its value was clear: once reported, a case of the illness could be traced, treated, and, if necessary, confined. But what could be done with a cancer patient? The traditional role of surveillance in stopping the spread of illness seemed not to apply. There was little possibility of intervening at the population level because the cause, or causes, of the condition remained baffling and were thus hotly disputed.<sup>13</sup> As a consequence, surveillance more commonly took the form of hospital-based registries, which did not measure incidence or prevalence but rather provided detailed information on selected groups of patients. Given such medical support for cancer surveillance, concerns about patient privacy was never a barrier to reporting. Cancer surveillance remained technically difficult and funding such efforts was problematic.

The founding in 1937 of the National Cancer Institute (NCI) within the U.S. Public Health Service provided a spur to state-based surveillance efforts.<sup>14</sup> Most were ‘incidence-only’ registries that did not follow cases over time. Named reporting was the norm since many patients were seen by more than one physician or hospital, and names and addresses were needed to avoid duplicate reports.<sup>15</sup> By 1948, cancer was reportable in 24 states.<sup>16</sup> But only in a few states, such as New York, Massachusetts, and Connecticut, was there anything close to complete reporting. The remaining half the states took no action on cancer. Some turned to the NCI for help in setting up registries, but they did not find a receptive audience in Bethesda. NCI saw basic molecular and biological research as the most promising path to the conquest of cancer, and had little use for traditional public health approaches. Reviewing the approach to cancer that prevailed during the middle decades of the century, Raymond Kaiser, director of the NCI’s cancer control branch, later recalled that cancer researchers ‘were never convinced that [cancer] ought to have been in the realm of public health activities... It’s okay for [health departments] to keep statistical records and maintain their tumor clinic records and that sort of thing, deaths and so forth, and maybe do

<sup>12</sup> Judith W. Leavitt, *Typhoid Mary: Captive to the Public's Health* (Boston: Beacon Press 1996).

<sup>13</sup> James T. Patterson, *The Dread Disease: Cancer and Modern American Culture* (Cambridge: Harvard University Press 1987).

<sup>14</sup> *Ibid.*, pp. 114-136.

<sup>15</sup> *Ibid.*

<sup>16</sup> Austin V. Diebert, ‘A Half Century of State Cancer Legislation’, *Public Health Reports* 63, no. 35 (August 27, 1948), 1128-1135, [www.ncbi.nlm.nih.gov/pubmed/18878264](http://www.ncbi.nlm.nih.gov/pubmed/18878264) (accessed March 11, 2010).

some epidemiological studies, but that was usually thrown in as an afterthought.<sup>17</sup>

The 1960s ushered in increasing societal attention to cancer, particularly as the rising burden of lung cancer captured public attention. But it was not until the 1970s that these concerns translated into concrete public policy. Although it had the flavor of an afterthought, the National Cancer Act of 1971 directed the NCI to ‘collect, analyze, and disseminate all data useful in the prevention, diagnosis, and treatment of cancer.’<sup>18</sup> An expert panel recommended the creation of SEER: the Surveillance, Epidemiology, and End Results Program. Its purpose was to determine cancer incidence and prevalence nationwide and in selected regions, to gain information on cancer survival trends in various types of cancer, and to identify etiological factors that might warrant further study.<sup>19</sup> But while the creation of SEER marked a turning point in the ability to ascertain the extent of cancer nationwide, it presented only a broad-brushstroke picture of the nation’s cancer situation, one that was largely insensitive to regional or local variation.

As the environmental movement, initially sparked by Rachel Carson’s controversial landmark book *Silent Spring*, gained momentum in the 1970s into the 1980s, concern about the effect of contaminants in the environment increasingly gripped the popular imagination. The media became preoccupied with reports of suspected ‘cancer clusters,’ such as the cases of childhood leukemia in Woburn, Massachusetts, that led to civil suits against R.W. Grace and Beatrice Foods and were subsequently dramatized in the book and movie *A Civil Action*. In 1978 and 1979, the twin catastrophes of Love Canal – the upstate New York neighborhood built atop a toxic waste dump and subsequently dubbed a ‘public health time bomb’ – and Three Mile Island – the nuclear power plant in Pennsylvania that suffered a partial meltdown – captured national attention.<sup>20</sup> But while the most riveting moments of dramas like Love Canal involved homeowners taking federal hostages in a bid to have the community relocated, the most demanding work of the movement required that community members themselves do the epidemiological fieldwork necessary to document the health consequences of toxic exposure. They understood that what doesn’t get counted doesn’t count.<sup>21</sup>

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<sup>17</sup> Lester Breslow, *A History of Cancer Control in the United States, 1946-1971* (Washington, D.C.: U.S. Public Health Service 1977).

<sup>18</sup> *Ibid.*

<sup>19</sup> Carol H. Johnson, ‘The Surveillance, Epidemiology, and End Results Program’, in: Carol L. Hutchison, Herman R. Menck et al. (eds.), *Cancer Registry Management: Principles and Practice* (Alexandria, VA: National Cancer Registrars Association, Inc. 2005).

<sup>20</sup> Steven P. Schwartz, Paul E. White & Robert G. Hughes, ‘Environmental Threats, Communities, and Hysteria’, *Journal of Public Health Policy* 6:1 (March 1985), 58-77.

<sup>21</sup> Lois Marie Gibbs, *Love Canal and the Birth of the Environmental Health Movement* (Island Press, 1982).

Around the country, communities in the 1980s clamored for better information on their cancer incidence. The American Cancer Society, which conducted no surveillance of its own, felt ‘a constant press for local data.’<sup>22</sup> Such concerns about cancer in the environment led to a flurry of political activity, as lawmakers around the country moved to make cancer a reportable condition, and more than a dozen states created registries to track cancer incidence.<sup>23</sup> Over the next decade these new statewide registries were used in analyses of several high-profile cases of suspected clusters. Many of these investigations refuted or failed to confirm suspected links between a given environmental contamination and cancer, but such investigations implicitly gave priority to the public’s right to know about the hazards to which they were exposed. More broadly, the activity around cancer reporting beginning in the mid-1970s threw into sharp relief the extent to which state public health departments lagged in dealing with cancer and chronic diseases more generally. Although by 1985 some 31 states had established registries, only five had robust cancer control programs.<sup>24</sup>

During the 1980s, the breast cancer patient activist movement gained prominence, exemplified by the work of pioneering activist Rose Kushner, whose 1979 memoir *Why Me?* represented a watershed in the movement for greater patient empowerment. Activists were inspired by the examples of Kushner and public figures who ‘came out’ as breast cancer survivors, such as first lady Betty Ford; Happy Rockefeller, wife of New York governor Nelson Rockefeller; and the journalist Betty Rollin, who wrote of her experiences with the disease in her memoir *First You Cry*. By writing and speaking publicly about their experiences, women with cancer sought to remove the shame and silence they saw as surrounding the disease; they shed the anonymity afforded by older conceptions of paternalistic privacy as they entered the political process to challenge existing treatment paradigms and demand a greater role in medical decision-making. Transforming ‘the personal into the political,’ they also demanded to be counted.<sup>25</sup> The black feminist writer Audre Lorde, who noted the ways that the silence surrounding cancer became deafening when compounded for gay women of color, captured a shared sense of urgency when she argued, ‘We must count the living with that same particular attention with which we

<sup>22</sup> Phyllis Wingo, interview with James Colgrove, September 8, 2005.

<sup>23</sup> John P. Enterline, Anne Kramer, Ellen B. Gold et al., ‘United States Cancer Reporting Laws: Structure and Utility’, *American Journal of Public Health* 74:5 (May 1984), 449-452, <http://ajph.aphapublications.org/cgi/reprint/74/5/449> (accessed March 11, 2010); Holly Howe, interview by author, North American Association of Central Cancer Registries, August 11, 2005.

<sup>24</sup> Helen I. Meissner, Lawrence Bergner & Katherine M. Marconi, ‘Developing Cancer Control Capacity in State and Local Public Health Agencies’, *Public Health Reports* 107:1 (January-February 1992), 15-23.

<sup>25</sup> Barron H. Lerner, *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth-Century America* (New York: Oxford University Press 2001).

count the dead.<sup>26</sup> A key claim of activists was that the government was devoting paltry financial resources to a problem of unrecognized magnitude. Surveillance thus became a lever in a struggle for greater government funding that would drive research agendas.

In 1990 the National Breast Cancer Coalition was formed, under the leadership of the well-known surgeon Dr. Susan Love, and the following year the group launched a grassroots letter-writing campaign in which people across the country flooded the White House with letters urging the federal government to devote more funding for breast cancer research.<sup>27</sup> As this campaign was under way, a group of breast cancer activists in Vermont – one of the states that had no cancer registry – pushed forward the issue of greater surveillance. Two breast cancer survivors in the state organized a letter-writing campaign focused on establishing universal cancer reporting. Although most states had some type of central cancer registry by this point, most of these had only partial coverage of total cancer incidence in the state. Ten states had no registry at all.<sup>28</sup>

Early in 1992, at the insistence of activist Pat Barr and several other breast cancer survivors, legislation that would establish a national program to collect data on cancer incidence was introduced in the House and Senate. Speaking in support of his bill on the floor of the House of Representatives, Bernie Sanders – a Socialist, one of Congress' most liberal members, and its only registered Independent – repeatedly invoked claims of a public 'need to know.' 'Clearly, if we are going to be effective in fighting cancer in general, and breast cancer specifically, we need more information – we need better than estimates,' Sanders declared. 'Our researchers need information that they do not have today ... We need to know the age of people who are coming down with cancer. We need to know where they live. We need to know the kind of work they do. We need to know their racial and ethnic backgrounds. We need to know the relationship between early detection and the success of treatment. In other words, we need as much information as we can gather.'<sup>29</sup> With strong support from the Congressional Caucus for Women's Issues and from representatives of states in the Northeast and mid-Atlantic, where the issue had special urgency because of data suggesting that these regions had breast cancer mortality rates in excess of other areas of the country, the measure sailed through both the House and Senate. President George H.W. Bush signed the Cancer Registries Amendment Act, which authorized the Centers for Disease Control and Preven-

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<sup>26</sup> Audre Lorde, *The Cancer Journals* (Aunt Lute Books 1980), 49.

<sup>27</sup> Lerner, *op. cit.*

<sup>28</sup> Judith Swan, Phyllis Wingo, Rosemarie Clive et al., 'Cancer Surveillance in the U.S.: Can We Have A National System?', *Cancer* 83:7 (October 1, 1998), 1282-1291.

<sup>29</sup> Bernie Sanders, *Testimony, United States House of Representatives*, 102nd Cong., 2nd Session, Congressional Record – Extension of Remarks 138, Washington, D.C., February 25, 1992.



tion to set up a program to provide financial and technical support for population-based cancer registries in every state, into law in October 1992.<sup>30</sup>

In this new era, both patient privacy and how to protect the security of registry data – which often contained detailed patient information by name and address from the time of first diagnosis – became a central issue that would shape the politics of cancer surveillance at the century's end. Before states could receive federal funding, they had to have laws in place that provided for the confidentiality of the registry data.<sup>31</sup> In 1993, only nine states had all the statutes in place that the CDC deemed essential.<sup>32</sup> By 2000, all states had established statewide population-based registries, most of which tracked cancer incidence only, yet as universal reporting of cancer became a reality, it was against a backdrop of heightened public concern about the sharing of medical information. Conflicts over access to registry data played out in public meetings, legislatures, and courtrooms. Communities wanted access to the data. Patients themselves did not want their names disclosed, of course, but many also believed that a too-strict commitment to privacy could hamper the usefulness of registries, while others felt they had a right to choose whether or not to be included in a registry. 'One of the complaints that was heard from consumers was that people don't know that the cancer registry exists,' recalled Janice Platner, a breast cancer survivor in Massachusetts who served on the state registry's advisory committee. 'It's not even an issue of consent so much as knowledge that their information goes to the cancer registry ... People get a call out of the blue saying we're doing this research on blah blah blah. Some people get quite upset. How did they get my name? Where did that come from?'<sup>33</sup> In some states, such as Massachusetts and Virginia, efforts were consequently made to seek informed consent for cancer surveillance – a measure that both cancer activists and surveillance staff typically resisted, not because they did not value privacy, but to protect the validity of the database.<sup>34</sup> Debates would prompt an editorial in the *New England Journal of Medicine* to declare that 'Public health is threatened by

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<sup>30</sup> Mary D. Hutton & Gayle Greer Clutter, 'The National Program of Cancer Registries', in: Carol L. Hutchison, Herman R. Menck et al. (eds.), *Cancer Registry Management: Principles and Practice* (Alexandria, VA: National Cancer Registrars Association, Inc. 2005), 17-26.

<sup>31</sup> Cancer Registries Amendment Act, 1992, *Public Law* 102-515, 102d Cong. (October 24, 1992).

<sup>32</sup> Centers for Disease Control and Prevention, 'State cancer registries: status of authorizing legislation and enabling regulations – United States, October 1993', *MMWR Morbidity and Mortality Weekly Report* 43:4 (February 4, 1994), 71-75.

<sup>33</sup> National Committee on Vital and Health Statistics, U.S. Department of Health and Human Services, *Transcript of Roundtable Discussion on Health and Medical Registries, Subcommittee on Privacy and Confidentiality* (Washington, D.C. January 29, 1998), [www.ncvhs.hhs.gov/980129tr.htm/](http://www.ncvhs.hhs.gov/980129tr.htm/) (accessed March 11, 2010).

<sup>34</sup> Joint Commission on Health Care, Virginia General Assembly, Cancer Registry Study Pursuant to HJR 524 and SB 942, House Document No. 73 (Richmond, VA 2000).

incomplete data more than individual privacy is threatened by disease registries.<sup>35</sup>

The same forces that created alliances between grassroots activists and health officials and catalyzed the creation of many state registries – popular concern about incidence of cancer in communities – would also bring citizens in new kinds of conflict with public health departments as they sought to balance their duties to the public with their responsibility to protect individuals listed in registries. The most contentious and protracted controversy unfolded in Illinois, which in 1986 had created a ‘health and hazardous substances’ registry – a set of linked databases collecting information on birth defects, occupational diseases, and cancer – to track conditions potentially related to environmental hazards. Within two years of its founding, a tug-of-war over the data began between the health department and community members. After four cases of neuroblastoma, a rare cancer, were diagnosed in children in Taylorville, in southern Illinois, the children’s parents suspected the illnesses were caused by exposure to coal tar, a known carcinogen that was released into the environment during the cleanup of an energy plant in the community. The parents sued the utility company responsible for the plant; in addition, one of the mothers filed a Freedom of Information Act request asking the state cancer registry to release data on leukemia and childhood cancer in the county. The request did not ask for patient names, but did ask for data broken down by ZIP code, year of diagnosis, and type of cancer.<sup>36</sup> The state health department refused, arguing that even in the absence of names, the identities of individual patients could be inferred from those three pieces of information. It offered instead to release the data but with the county of residences substituted for ZIP code – a compromise unacceptable to the parents. The case ultimately ended up in a state appellate court.

In determining whether the data should be released, the judges sought guidance from the legislative language of the Act that created the registry – language that bore the clear imprint of public concerns over cancer. The purpose of the registry was to ‘inform and protect the citizens of Illinois’; further, the Act explicitly stipulated that ‘all information contained in the Registry shall be made available to the public upon request.’<sup>37</sup> At the legal heart of the matter was the interpretation of a section of the Act regarding privacy. ‘The identity, or any group of facts *which tends to lead to the identity*, of any person whose condition or treatment is submitted to the Illinois Health and Hazardous Sub-

<sup>35</sup> Julie R. Ingelfinger & Jeffrey M. Drazen, ‘Registry Research and Medical Privacy’, *New England Journal of Medicine* 350:14 (April 1, 2004), 1452-1453, <http://content.nejm.org/cgi/content/full/350/14/1452> (accessed March 11, 2010).

<sup>36</sup> Joe Mahr, ‘Neuroblastoma appeal ready for state’s high court’, *The State Journal-Register* (May 16, 2000).

<sup>37</sup> *May v. Central Illinois Public Service Co.*, 260 Ill. App. 3d 41 (1994), 45.

stances Registry is confidential and shall not be open to public inspection or dissemination.<sup>38</sup> Would the pieces of information requested by the Taylorville mothers ‘tend to lead’ to the disclosure of identities in the registry? The judges in the case determined that they would not, and after the department failed to comply with a subpoena demanding the data, a judge held state health commissioner John Lumpkin in contempt of court. Lumpkin eventually negotiated a compromise under which the expert who would analyze the data would protect patient confidentiality.<sup>39</sup>

That agreement did not end the story, however. The controversy was reopened – with essentially the same issues at stake – in 1997, when the newspaper *The Southern Illinoian* asked the registry to provide data on the incidence of neuroblastoma from 1985, again without names but with ZIP code and date of diagnosis. As it made its case for access, the paper stated, ‘If there are clusters of neuroblastoma in Southern Illinois...we want to know that.’<sup>40</sup> The health department’s refusal to turn over the data, on the same grounds as before, reignited the debate over whether fragments of information from the registry were sufficient to identify individual patients.

The centerpiece of this new trial was the testimony of a Carnegie Mellon University professor who served as an expert witness for the health department who testified that, through a six-step matching process using a standard laptop computer and commercially available software, she had been able to identify a single correct individual for eighteen of the twenty cases provided to her. The Department of Public Health defended their continued shielding of the registry data by arguing that ‘one does not need to be a professor from MIT’ to determine the identities in the data sets. Yet a three-judge panel on the appellate court rejected the state’s ‘alarmist conjecture.’<sup>41</sup> It asked: ‘Are there two people in the entire state of Illinois who could replicate [these] results with the same limited data or are there two thousand? Are there zero or are there a million?’ These questions are significant because without some sense of the magnitude of the alleged threat ... it is very difficult for this court to determine whether the data in question reasonably tends to lead to the identity of specific persons.’<sup>42</sup> In 2004, the three appellate judges affirmed a lower court ruling ordering the release of the data, and in early 2006, the Supreme Court of Illinois unanimously

<sup>38</sup> *Ibid.*, emphasis added.

<sup>39</sup> Tony Cappasso & Frank Fuhrig, ‘Most of Expert’s Bill for Work Trying to Get State Cancer Data’, *The State Journal-Register* (January 12, 1998).

<sup>40</sup> *Southern Illinoian*, a Div. of Lee Enterprises, Inc. v. Department of Public Health, 319 Ill. App. 3d 979, 747 N.E.2d 401 (Ill. App. 5 Dist. 2001).

<sup>41</sup> *Southern Illinoian*, a Div. of Lee Enterprises, Inc. v. Department of Public Health, 349 Ill. App. 3d 431, 812 N.E.2d 27 (Ill. App. 5 Dist. 2004).

<sup>42</sup> *Ibid.*

upheld the verdict.<sup>43</sup> The publisher of the *Southern Illinoisan* declared the ruling a victory for ‘the public’s right to know.’<sup>44</sup>

## HIV: The Right to Resist

If the battles over cancer gave expression to the way in which surveillance could serve the interests of those who were the objects of case reporting, the battle over AIDS and HIV for almost two decades at the end of the twentieth century made clear how those who had been the subjects of hatred, discrimination, stigma, and neglect could view surveillance as a threat.

In June 1981 the Centers for Disease Control began to report on the appearance in previously healthy gay men of diseases that in the past had occurred only in individuals with compromised immune systems. The CDC’s official publication *Morbidity and Mortality Weekly Report* recounted that between October 1980 and May 1981 five young men had been diagnosed with *pneumocystis carinii* pneumonia.<sup>45</sup> By way of explanation, the CDC noted the possibility that some aspect of homosexual lifestyle or disease acquired through sexual contact might be involved.<sup>46</sup> One month later the CDC reported that in the prior two and a half years, Kaposi’s sarcoma, a malignancy rare in the United States, especially in young people, had been diagnosed in 26 gay men in New York and California.<sup>47</sup> These were sentinel cases of an epidemic that would have a profound impact on gay men, intravenous drug users and their sexual partners, and on African American and Latino communities in the last two decades of the twentieth century.

Sharing the perplexity of clinicians and public health officials about what could be assaulting the immune system of previously healthy gay men, leading to suffering and death, those who spoke on behalf of gay men supported reporting of AIDS cases by name to state public health registries. AIDS was like cancer here. The story was very different with the HIV virus that causes AIDS. Soon after HIV was identified as the etiological agent responsible for AIDS in 1984, an assay was developed to detect antibody to the virus. The first encounter over a proposal for HIV name reporting took place in New Jersey just a month after the screening of blood donations began nationwide in April 1985.<sup>48</sup>

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<sup>43</sup> *Ibid.*

<sup>44</sup> Associated Press, ‘State high court rules cancer records must be released’ (February 3, 2006).

<sup>45</sup> Centers for Disease Control and Prevention, ‘Pneumocystis pneumonia – Los Angeles’, *MMWR Morbidity and Mortality Weekly Report* 30:21 (June 5, 1981), 250-252.

<sup>46</sup> *Ibid.*

<sup>47</sup> Centers for Disease Control and Prevention, ‘Kaposi’s sarcoma and Pneumocystis pneumonia among homosexual men – New York City and California’, *MMWR Morbidity and Mortality Weekly Report* 30:25 (July 3, 1981), 305-308.

<sup>48</sup> *New York Native*, June 3-16, 1985.

Drawing a sharp distinction between reporting cases of AIDS and the results of the new antibody test, with its still ambiguous clinical implications – *Were all those who tested positive infectious? What proportion would progress to full-blown AIDS?* – the local gay community denounced the proposal. Opposition came also from the national Federation of AIDS-Related Organizations and the United States Conference of Local Health Officers.<sup>49</sup> Confronted with so determined an opposition, the New Jersey Public Health Council decided to defer to the legislature (*New York Native* 1985). It was the first of many encounters between activists and health officials in many states who began to argue the case for HIV reporting for the purposes of monitoring the epidemic.

The first successful attempts to mandate public health reporting of HIV antibody test results came in Minnesota, Wisconsin, and Colorado, three states with low-level epidemics and gay communities far less politically potent than those in California and New York.<sup>50</sup> These states would bear witness to the democratization of privacy, underscoring the ways in which the broader culture could shape the politics of privacy across different domains. The conflict that erupted in Colorado was typical of those that would occur in other states as they attempted to move toward name reporting for HIV. In August 1985, Thomas Vernon, the executive director of the Colorado Department of Health, proposed that the state require HIV reporting.<sup>51</sup> It would allow agencies to insure that infected persons were properly counseled about the significance of their laboratory test results and about what they needed to do to prevent further transmission of the virus. Reporting would also create the possibility of expeditiously notifying the infected when effective antiviral therapeutic agents became available. Every traditional public health justification for reporting applied, according to Vernon, to infection with HIV. A failure to extend reporting to this situation would thus represent a dereliction of professional responsibility in the face of a new deadly disease. Responding to concerns about breaches in confidentiality that could result in social ostracism, loss of insurability, and loss of employment, Vernon and his deputy for sexually transmitted diseases asserted that the system for protecting such public health records had been effective for decades. There was no reason to believe that in the case of infection with the AIDS virus the department's record would be tarnished.

Despite Vernon's belief that his proposal was in the grand tradition of public health measures, his efforts provoked a sharp response from his opponents in a hearing before the state's Board of Health.<sup>52</sup> The director of public health for Denver warned that reporting would have the counterproductive impact of

<sup>49</sup> United States Conference of Local Health Officers, letter to Ronald Altman, 1985.

<sup>50</sup> Ronald Bayer, *Private Acts, Social Consequences: AIDS and the Politics of Public Health* (New York: The Free Press 1989).

<sup>51</sup> Thomas Vernon, interview with Amy Fairchild and Ronald Bayer (Denver, CO 1986).

<sup>52</sup> Colorado Board of Health, Minutes (Denver, CO. August 21, 1985).

driving high-risk individuals away from testing, regardless of the health department's pledges to preserve the confidentiality of test results. The director of the gay community-based Colorado AIDS Project asserted that his organization would not encourage testing if Vernon's proposal were adopted. The president of the board of Colorado's Civil Liberties Union joined the challenge. In each case, Vernon's opponents underscored their fear that, regardless of the historical and prevailing standards of confidentiality, a repressive turn caused by the hysteria associated with AIDS could well result in social policies that Vernon and his associates would consider anathema. To these concerns Vernon responded with a claim that he was to make repeatedly in the next months: widespread perception that public health officials had failed to do 'everything possible' to control AIDS could foster social anxiety and thus produce the very repression so feared by those concerned with the rights of the infected.

In the face of bitter protests by gay and civil liberties groups, as well as the concern of some health officials, one month after Vernon made his proposal, the Board of Health nonetheless unanimously adopted a resolution making Colorado among the first to require the reporting by name of those testing positive for antibody to HIV.<sup>53</sup> To those who continued to stress the possibility that the health department's list of seropositive individuals could be put to ill use, Vernon responded, 'The issue before us is the reality of a tragic epidemic of AIDS, not the theoretical risks [that] our confidentiality system will be breached.'<sup>54</sup>

Activists in Colorado burned Vernon in effigy, foreshadowing the bitter protests that would follow in high-incidence states. Describing a meeting on reporting sponsored by the AIDS Action Council that brought together health department officials from a number of states and AIDS activist groups, two CDC officials wrote, 'It became clear that there was a lack of trust in government at almost every level in dealing with HIV issues.' The words of an oft-repeated Act-Up chant used to protest New York City Health Commissioner Stephen Joseph's failed efforts to institute HIV reporting summarized the view of many of those representing nongovernmental organizations: 'First you don't exist, then you're on Joseph's List.'<sup>55</sup>

Aware of the depths of resistance with which it had to deal and the extent to which the battle over names was impeding the task of extending surveillance activities beyond AIDS case reports, the CDC commenced a series of public broad-based consultations in early 1993. In part, such efforts intended to convey that decision-making regarding AIDS policy was both transparent and democratic – a rejection of the authoritarian traditions of public health – permitting

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<sup>53</sup> *Ibid.*

<sup>54</sup> *Rocky Mountain News*, October 13, 1985.

<sup>55</sup> *ACT UP Reports* 4 (June 1989), 1.

those with important interests to speak and be heard. But as important, such sessions were designed to determine how best to narrow the grounds of disagreement, yielding ground on matters such as the ways in which the security of surveillance data could be protected from breaches of confidentiality and assuring that case reports could be used solely for legitimate public health purposes without giving way on the central commitment to name-based notification to state health departments. HIV thus underscored the extent to which democratic participation was not synonymous with popular rule.

By the end of the first decade of AIDS epidemic, the political terrain began to change. The clinical context against which the initial debates about the most appropriate forms of public health surveillance occurred was grim. But in 1994 a clinical trial with the antiretroviral drug AZT in pregnant women demonstrated the possibility of reducing transmission from mother to fetus by two thirds, from 22 percent to 8 percent.<sup>56</sup> In 1995 even more startling results demonstrated that a new class of drugs – the protease inhibitors – when used in combination with other antiretroviral agents could reduce viral loads in infected individuals to undetectable levels and could have a dramatic impact on the clinical course for those with HIV disease. The first decline in reported cases of AIDS and AIDS-related deaths in the United States since the epidemic's onset came in 1996.<sup>57</sup>

These therapeutic advances, which were to have an extraordinary impact on the lives of people infected with HIV, profoundly affected the debate on surveillance. Since the new therapeutic paradigm suggested the importance of early identification of people with HIV, it became more crucial than ever to encourage wide-scale testing and to refer those with infection to clinical services. For advocates of HIV name reporting it was clear that now the very lives of the infected depended on case notification. Opponents saw the situation very differently. Case reporting by name would almost certainly scare people away from testing and thus pose a danger to life itself. Further, anything that placed in jeopardy the publicly funded anonymous testing sites created in the mid-1980s as a lure to those who wished to shield their identities – in some states HIV case reporting went hand in hand with the closure of such centers – had to be resisted.

But about one issue there was little dispute: AIDS case reporting could no longer serve as an adequate measure of the state of the epidemic. Since the new therapies delayed the onset of AIDS-defining illnesses by years, case reporting of AIDS revealed a pattern of infection increasingly remote from current patterns

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<sup>56</sup> Edward M. Connor, Rhoda S. Sperling, Richard Gelber, Pavel Kiselev, Gwendolyn Scott et al., 'Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment', *New England Journal of Medicine* 331:18 (November 3, 1994), 1173-80, <http://content.nejm.org/cgi/content/short/331/18/1173> (accessed March 11, 2010).

<sup>57</sup> Centers for Disease Control and Prevention, *AIDS Surveillance – General Epidemiology* (Atlanta, GA, 2000), [www.cdc.gov/hiv/graphics/surveill.htm](http://www.cdc.gov/hiv/graphics/surveill.htm) (accessed March 11, 2010).

of HIV infection. It produced a picture of the epidemic that was a decade out of date. Public health officials at state, local, and federal levels began to press publicly for name reporting of HIV. Some were motivated by the belief that partner notification – a long-standing method to reach individuals potentially exposed to other sexually transmitted diseases – was crucial to reach those who did not know that they may be infected with HIV. And the unspoken rationale for adopting more aggressive surveillance strategies was the changing face of AIDS. It was now injecting drug users, blacks, and Latinos who bore the brunt of the epidemic.

As the prospect of HIV case reporting loomed, significant fissures began to emerge in the alliance that had so steadfastly resisted such a move. A consultative session convened by the Council of State and Territorial Epidemiologists and the CDC in mid-year provided the occasion for those divisions and shifts in opinion to be made public.<sup>58</sup> Placing the new alignment into bold relief was an exchange between two veterans of the surveillance wars: Neil Schram, a gay physician who had headed the American Association of Physicians for Human Rights in the epidemic's early years and who had steadfastly opposed HIV reporting for more than a decade, and Jeff Levi, who as head of the National Gay Task Force in the 1980s and who as a senior official at the AIDS Action Council, had given voice to the primacy of privacy for gay men. At the consultation Schram not unexpectedly explained why the gay and bisexual community would never support name reporting, especially when linked to partner notification – the public health measure of reaching out to the sexual and needle-sharing partners of individuals infected with HIV so that they could also get tested and, if necessary, receive treatment.

Jeff Levi took a fundamentally different position. It was no longer possible, he said, to speak of unanimity on the issue of reporting in the gay community. While acknowledging the persistence of American homophobia, he believed that 'we are in a different place than we were when we first had the discussions 15 years ago.' Both the 'science and sociology' of the epidemic had undergone a fundamental change. How, he asked, could AIDS advocates press government to expand the range of social and medical services to people with HIV and at the same time oppose name reporting because of a lack of trust? Then, echoing a perspective that had characterized many African American AIDS spokespersons who had often been more concerned about access to life-saving care than privacy, he noted that, after HIV testing, patients ideally would be referred to primary care, possibly in a public clinic with services covered by Medicaid. There 'they have your name, your address, your Social Security number, your entire medical history, your HIV status, your CD4 count, your viral load ... So

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<sup>58</sup> Consultation on the Future Direction and Practice of HIV Infection and AIDS Case Surveillance in the United States (document in possession of author, not dated).



we trust the government to have everything there is to know about us when it comes to care.’<sup>59</sup>

It was on this terrain of shifting perspectives that the Council of State and Territorial Epidemiologists finally moved to call definitively for name reporting.<sup>60</sup> And in September 1997, the CDC formally announced that it would call upon all states to adopt a system of HIV case surveillance.<sup>61</sup> To demonstrate the broad-based support for change it had long sought, John Ward, a senior surveillance official at the CDC, joined with Lawrence Gostin, a Georgetown Law Professor with a history of advocacy for civil liberties, and Cornelius Baker, the African American AIDS activist, to coauthor an editorial published in the *New England Journal of Medicine*. ‘We are,’ they asserted, ‘at a defining moment of the epidemic ... Unless we revise our surveillance system, health authorities will not have reliable information about the prevalence of infection ... We propose that all states require HIV case reporting.’<sup>62</sup>

But the aura of inevitability and consensus could not mask the persistence of bitter opposition to name reporting. The ACLU brought its considerable intellectual and political resources to the fray: ‘There may come a time when HIV is so unremarkable a part of our social landscape and care for it is so routinely available to those who need it, that no one will reasonably fear being identified as a person with HIV. But we are nowhere close to that yet. On the contrary, the best evidence we have suggests that those who most need HIV testing are afraid of name reporting because they fear discrimination. Moreover, we know those fears are not groundless.’<sup>63</sup> As the CDC began what would ultimately be a more than two-year process of developing a set of recommendations for states on HIV case reporting, it, too, was faced with divisions among its senior personnel.<sup>64</sup> Those involved directly in surveillance activities were firmly convinced that only a name-based system would be effective. By contrast, among those primarily engaged in prevention activities – where direct, ongoing contact with at-risk communities defined the work environment – there was much greater sympathy for the oft-expressed concerns and fears about the dangers of stigmatization and discrimination. Even when such officials did not themselves think

<sup>59</sup> *Ibid.*

<sup>60</sup> Council of State and Territorial Epidemiologists, Position statement 1997-ID-4, National HIV Surveillance: Addition to the National Public Health Surveillance System (document in possession of author, 1997).

<sup>61</sup> Centers for Disease Control and Prevention, ‘Update: trends in AIDS incidence – United States, 1996’, *MMWR Morbidity and Mortality Weekly Report* 46:37 (September 19, 1997), 861-867.

<sup>62</sup> Lawrence O. Gostin, John W. Ward & A. Cornelius Baker, ‘National HIV Case Reporting for the United States – A Defining Moment in the History of the Epidemic’, *New England Journal of Medicine* 337:16 (October 16, 1997), 1162-67, <http://content.nejm.org/cgi/content/full/337/16/1162> (accessed March 11, 2010).

<sup>63</sup> Matthew Coles, *HIV Surveillance and Name Reporting: A Public Health Case for Protecting Civil Liberties* (1997), 11.

<sup>64</sup> Kevin DeCock, phone interview with Amy Fairchild and Ronald Bayer (July 18, 2002).

the threats credible, they believed that respecting community fears was crucial for purposes of sustaining their all-important working relationships.

To be sure, the end of the two-year-long battle was not achieved without compromises that made allowances, although slim ones, for states to adopt coded reporting systems to protect anonymity, but on December 9, 1999, the CDC issued its final recommendations.<sup>65</sup> In the two years that elapsed since the CDC first signaled that it would be preparing national HIV case surveillance guidelines, nine states had adopted or begun the implementation of such notification. Demonstrating resistance to the CDC's own unmistakable predilection for name-based reporting, five states chose some variant of a coded system.

More powerful as an impetus for change than the CDC's guidelines was the action of Congress. The Ryan White CARE Act, first passed in 1990, provided a significant source of federal funds for treatment and care to those localities that had borne the brunt of the AIDS epidemic. With broad congressional support, the Act represented a singular commitment to providing a safety net for the most vulnerable people with AIDS. Inevitably, concerns emerged about the adequacy of the funding formulas to truly reflect the social burdens created by the epidemic. Did the resources reflect current AIDS needs or did they unfairly advantage those metropolitan areas where the epidemic had first struck? Were the needs of women and minority members being addressed adequately? In short, questions of equity persisted.

In 2000, as the Act was being reviewed for reauthorization, the adequacy of formulas based on AIDS cases became a focus of attention. Representative Tom Coburn, a Republican from Oklahoma, who had long argued for HIV name reporting, now pressed the need for a shift to HIV case reports. 'Those with HIV are too often not figured into the components of care.' The chair of the House Subcommittee on Health and the Environment stressed the need for 'reliable data on HIV prevalence' for meeting the Act's purposes. But the use of HIV surveillance was also supported by California's powerful liberal Democrat, Henry Waxman, a representative closely aligned with AIDS advocacy groups, many of which had begun to rethink the univocal opposition to HIV reporting in light of links between Ryan White dollars and the burden of HIV disease debate. In the end, the reauthorized Care Act directed that the formulas for the allocation of funds to state and 'eligible metropolitan areas' incorporate data on reported cases of HIV infection. Such data was to be used in allocations as early as fiscal year 2005 if the Secretary of Health and Human Services determined that the data was sufficiently accurate for resource allocation pur-

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<sup>65</sup> Centers for Disease Control and Prevention, 'Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome', *MMWR Recommendations and Reports* 48:RR-13 (December 10, 1999), 1-27, 29-31.

poses.<sup>66</sup> Technical assistance to the states would be provided to assure that case reporting met acceptable standards. The deadline for attaining the requisite level of proficiency was 2007. Congress remained silent on whether name reporting was more likely to serve the purposes of the Act. With billions of dollars in aid at stake it was not surprising that it would provoke a move to case reporting in those states that had yet to embrace HIV surveillance. In December 2003, Georgia – the home of the CDC – became the last state to adopt some form of case reporting.

### Conclusion: Finding the Commonality in Difference

The act of surveillance, as one scholar has argued, is Janus-faced: it is ‘as vital to the maintenance of our welfare and freedom’ as it is to ‘a policy of rounding up undesirable minorities.’ The interconnected politics of privacy and public health reporting, accordingly, have been shaped by group perceptions of the ‘freedoms’ and ‘unfreedoms’ that will flow from state efforts to track those with disease by name.<sup>67</sup>

While people with cancer demanded the right to be the *subjects* of surveillance, people with HIV sought *protection from* surveillance. Basic characteristics of the diseases and those who suffered from them as well as the potential for public health intervention help explain this apparent paradox. A central rationale of increased cancer surveillance was to enhance understanding of its etiology; HIV’s causative agent and modes of transmission were, by the mid-1980s, well known. Because HIV was infectious and fatal, surveillance carried the threat of triggering coercive, even draconian control measures. Further, people with HIV – gay and bisexual men and drug users and their sexual partners – were highly stigmatized; they feared they would be the targets of discrimination, even violence, should their condition become known. The middle- and upper-class women leading the charge for breast cancer reporting had no such concerns. Nonetheless, just like AIDS activists, cancer activities were required to break the silence about their own disease in order to press politicians to provide the funding for surveillance. Once that surveillance was established, both activists and concerned citizens could find themselves battling health officials for access to the data that could tell them whether or not they faced environmental threats in their communities.

On the one hand, then, in HIV and cancer we have two very different stories. In the context of HIV, privacy was a civil liberty that was critical to defend; in

<sup>66</sup> Institute of Medicine, *Measuring What Matters: Allocation, Planning, and Quality Assessment for the Ryan White CARE Act* (Washington, D.C.: The National Academies Press 2004).

<sup>67</sup> James C. Scott, *Seeing Like a State: How Certain Schemes to Improve the Human Condition Have Failed* (New Haven and London: Yale University Press 1998), 7.

the context of breast cancer, it would have to yield in the name of health. On the other, there is a common story of rights to tell, one that is easily masked by the extent to which AIDS activists resisted surveillance and cancer activists supported it. Profound uncertainty at the outset of the AIDS epidemic did, in fact, result in fairly rapid agreement that in the absence of name-based case reporting the mystery of what caused AIDS could not be solved. But while that consensus cracked when it came to testing people for the virus, determination to resist would be transformed into a story of the right to be counted once effective therapy was available. In the case of both cancer and HIV, the tension between privacy and surveillance brought activists concerned with two very different diseases, with two very different stances on privacy, into direct engagement with the politics of public health. Together they have been part of bringing about a critical historical change in which patients, their advocates, and concerned citizens more generally are all actively engaged in defining the benefits and limits of privacy and surveillance and, in addition, articulating a set of oft-unrecognized normative rights – the right to know and the right to be counted – that have marked the politics of public health for the past half century.