ISSUE: DISEASE SURVEILLANCE AND PRIVACY

The Question

Is there an inherent tension between disease surveillance and privacy? When public health officials invade an individual's privacy for the collection of information necessary to the protection of the public's health, do they unavoidably trigger a "trade-off among competing social, ethical, legal interests and values?"[1] Is there a way to gather such information while safeguarding the privacy of the individual? How is this debate influenced globalization, the threat of terrorism and advances in technological capabilities?

Definition: What is Surveillance?

Surveillance is the radar of public health. It is the name-based reporting of cases of disease (which requires the ongoing participation and cooperation of the public) to the data banks of state and local health departments. These departments use the data as the basis for program planning, implementation, and evaluation. Frequently used in the 19th century, surveillance has proven itself as a critical, effective tool in the 20th and 21st: it made possible the discovery that a single manufacturer of Salk vaccine caused cases of paralytic polio in 1955; that the outbreak of toxic shock syndrome in 1979 was linked to tampons; and that a new disease, AIDS was evident in the early 1980s in sentinel cases on the East and West coasts. Surveillance made possible the identification of West Nile virus, SARS, and Avian flu at the turn of the twenty-first century. Surveillance makes feasible the collection of data on cancer, birth defects and occupational disease, where the information is utilized to justify larger ameliorative resource allocations or interventions to improve workplace safety.

[1] Fairchild, Bayer and Colgrove, Searching Eyes: Privacy, The State, and Disease Surveillance in America, Berkeley, CA, University of California Press and The Milbank Memorial Fund, 2007, p. 252

Definition: What is the threat to Privacy?

When names are given to a public agency, the expectation may be that they will only be used for public health purposes. However, in the event of intentional or unintentional breaches in security, the connection of names to health data may be a facilitating source of discrimination by insurers, employers, other public officials—or even families or friends. In an era of anti-terrorism campaigns, heightened focus on public security, and even personal identity theft, the uses of private data cannot be guaranteed.

Background

In the United States, the American commitment to the rights of the individual and of a right to privacy is entrenched, extending from such factors as our immigrant cultural antecedents, the Bill of Rights, and the Supreme Court's decision in *Griswold vs. Connecticut.* At the same time, we acknowledge the value derived from invasions of privacy taken to protect the public's health, such as during epidemics of cholera, typhoid fever, tuberculosis, venereal disease, polio, AIDS and SARS. But the way in which surveillance has been practiced has frequently been controversial. For example, "in the late nineteenth century, physicians resisted tuberculosis notification because they sought to protect their private patients from intrusion on the part of public health officials. In the 1990's gay men and other AIDS advocates resisted efforts to require name-based reporting of HIV because of fears of how public health registries could be used to foster discrimination in employment, housing, and insurance…[and] as a prelude to the imposition of quarantines."[2] Today, the resistors of surveillance include the ACLU; libertarians; anti-vaccination activists; and religious groups concerned that birth defects surveillance will serve as a prelude to abortion.[3] And yet, even strongly held positions on surveillance can change. When medical advances offered beneficial health therapies to those with AIDS, activists

[2] *Ibid,* 252
[3] *Ibid,* 254

reversed their views and became supportive of expanding AIDS registries as a means of improving access for the afflicted to drug treatments. Positions on surveillance and privacy are influenced not only by social mores, but by global developments such as the rise in terrorism, in travel and migration, and by scientific developments.

The Politics of Surveillance

Surveillance is bounded by both a promise and a specter. Name-based disease reporting can result in assistance but also in the loss of liberty. It can trigger public health control measures such as contact tracing, mandatory treatment, and quarantine. The threat of such intervention and long-term monitoring has provoked alarm and rendered surveillance suspect for those concerned about the unwarranted exercise of State authority in the name of public health.

At the turn of the twentieth century, as mentioned previously, physicians resisted reporting the names of their tuberculosis patients to health departments. They worried that while health officials might impose restrictive measures on patients, they could offer little in terms of clinical care to the afflicted. More recently, during the global experience with the first two outbreaks of SARS, health officials imposed quarantines on hospitals and entire neighborhoods, while the World Health Organization recommended restricted travel to places as disparate as Singapore and Toronto. In this instance, however, it was not simply the case that those with or exposed to a serious contagious disease temporarily lost their liberty or suffered economic losses: they also received essential medical care.

As often as surveillance has been resisted, then, it has also been embraced by those with disease. Although AIDS activists resisted disease reporting during the first decade of the AIDS epidemic, as treatment became available, surveillance came to be linked to the distribution of important resources. Likewise, the histories of cancer and birth defects surveillance have, for a century, been primarily marked by patient demand for reporting so that treatments could be evaluated and environmental threats identified and eliminated.

Hence, the politics of surveillance depend on a number of factors. Most critical has been the extent to which surveillance might serve to trigger public health interventions and the way such interventions have been viewed as either threatening or potentially beneficial. Consequently, the availability of effective therapies has played a major role in the acceptability of surveillance. Yet medical efficacy is not a sufficient explanation: some U.S. states still lack surveillance for HIV, birth defects, or cancer.

The Role of History

Public health surveillance is more than a technical undertaking measured by empirical results, insulated from politics and society. It is most fundamentally a social practice that is embedded within particular contexts. Thus reactions to disease reporting have often been colored by more general attitudes towards other types of State surveillance and intrusion into personal privacy. If, for example, the Cold War, McCarthyism, and, later, the Watergate scandal, shaped attitudes toward surveillance in the US in the decades after World War II, the post 9/11 war on terror frames attitudes in the present.

Epidemiologists and other public health professionals may be well positioned to offer technical advice on the type of surveillance to undertake—anonymous, blinded, name-based, or laboratory-based. However, as an undertaking requiring not only technical expertise but also political support, including acquiring the confidence and cooperation of the public, a broad and, indeed, historically robust understanding of the politics of surveillance is essential.

The Center's Impact on Policy

Based on its historical analysis of more than a century of tension and conflict between privacy and public health surveillance, historians and ethicists at the Center for the History and Ethics of Public Health have shaped national and international analyses of disease reporting. The Center for Disease Control and Prevention, and the World Health Organization, have already utilized the Center's works in setting policy recommendations. The following is a

selected list of the Center's publications to-date which have had either a direct or influential impact on public policy debates:

Amy L. Fairchild, Ronald Bayer, and James Colgrove with Daniel Wolfe, *Searching Eyes: Privacy, the State, and Disease Surveillance in America* (California, 2007).

CDC Grand Rounds, November 2007.

Amy L. Fairchild, Lance Gable, Lawrence O. Gostin, Ronald Bayer, Patricia Sweeny, Robert Janssen, "Public Goods, Private Data: History, Ethics, and the Uses of Personally Identifiable Public Health Information," *Public Health Reports*. 122;Supplement 1(2007):7-15.

Amy L. Fairchild and Ava Alkon, "Back to the Future? Diabetes, HIV, and the Boundaries of Public Health," *Journal of Health Policy, Politics, and Law* 32;4(July 2007): 561-593.

Amy L. Fairchild, "Diabetes and Disease Surveillance," *Science* 313;5784 (July 14, 2006): 175-176.

Amy Fairchild and Ronald Bayer, *The Ethics of Second Generation Surveillance* (Geneva: WHO, 2004). http://www.who.int/hiv/pub/epidemiology/sgs_ethical/en/.

Amy L. Fairchild and Ronald Bayer, "Ethics and the Conduct of Public Health Surveillance," *Science* 303; 5658 (January 30, 2004):631-632.

Lawrence O. Gostin, Ronald Bayer, and Amy L. Fairchild, "Ethical and Legal Challenges Posed By SARS: Implications for the Control of Severe Infectious Disease Threats," *JAMA* 290;4 (December 24, 2003):3229-3237.

Amy L. Fairchild, "Dealing with Humpty Dumpty: Research, Practice, and the Ethics of Public Health Surveillance," *Law, Medicine, and Ethics* 31;4(Winter 2003):615-623.

Ronald Bayer and Amy Fairchild, "Surveillance and Privacy," *Science* 290;5498(December 8, 2000): 1898-1899.

The Center and the Future

How do we meet the challenge of global transmission of diseases like avian flu and extremely drug resistant tuberculosis? While it is important to have a nuanced understanding of the history and politics of public health surveillance in the United States, globalization requires a more elaborate analysis. Such an endeavor requires that we understand the encounter between privacy and disease surveillance in nations with different political and social traditions. Liberal democracies, like the US, while respecting individual rights, may balance those rights against the public health in certain negotiated ways; developing nations, and even totalitarian regimes where both privacy and the common good may have very different meanings, may follow a very different course. For example, a key factor in the early SARS epidemic was China's refusal to

report cases to international agencies. A global analysis of the politics of public health also demands that we understand not only the different national contexts that give privacy and surveillance unique histories, but also the ways in which these different pasts shape global efforts, on the part of organizations such as the World Health Organization, to monitor the spread of disease across borders.

Having completed a model history of public health surveillance, set against the backdrop of changing notions of privacy, the Center for the History and Ethics of Public Health is now poised to lead an international and global analysis of the politics of surveillance that can pave the way for developing ethical guidelines for international public health reporting.

The Center will commission histories from engaged scholars in a number of key nations—the United Kingdom, France, Germany, Japan, Russia, Israel, South Africa, Brazil, China, and Vietnam—in order to map the terrain of privacy and surveillance internationally. Critically, country-based analysis will focus on the response surveillance for both infectious *and* chronic diseases. In other words, it is as important to understand encounters not only over diseases like tuberculosis or HIV, but also for cancer and diabetes.

The individual country-specific analysis, and the synthesis that the Center for the History and Ethics of Public Health will subsequently provide, will represent the foundation for an international conference considering the political potential and ethical limits of the global monitoring of disease. In framing ethical issues in historical terms, we will set into bold relief the need to consider not simply empirical evidence about disease transmission or the efficacy of potential surveillance strategies and related interventions but the critical contextual issues that shape the social meaning of disease, including the appropriate responses to containing outbreaks or ameliorating morbidity and mortality while retaining the confidence and cooperation of the public. This conference will provide a venue in which critical historical perspective can serve as the basis for a robust discussion amongst historians, public health officials, clinicians, and

scientists focusing on a public health challenge requiring immediate attention. The recent SARS epidemics underscore the degree to which such systems are essential, as well as the challenges engaged by surveillance.

The Needs of the Center

Federal and International agencies are the typical sources of funding for time-limited analysis of narrowly defined public health challenges. For example, the National Cancer Institute may fund a project that considers debates over the creation of tumor registries or the controversies that have arisen regarding the appropriateness of sharing with a concerned public data related to potential "cancer clusters," but it is unlikely to extend that analysis to infectious conditions. An understanding of chronic disease surveillance is necessarily incomplete it if it is not part of the broader social tapestry including an appreciation of the context underlying issues of privacy.

The Center for the History and Ethics of Public Health is preparing to undertake a sustained analysis of this critical aspect of global public health. The scope should not be narrowed in deference to the specific agendas of various national funding agencies. As this ongoing analysis is part of the central mission of a core of faculty within the Center, it is essential to secure the stable salary and resource support so that they can focus consistently on this work and engage these issues with a broad network of scholars and professionals.

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The Center's Position:

Although there is an inherent tension between surveillance and privacy, it is neither possible nor even desirable to resolve it formulaically. The viability of democratic communities requires an ongoing effort to educate the constituencies involved and to promote a process whereby those constituencies negotiate and renegotiate the boundaries between privacy and public health, ensuring a full accounting not only of the potential of surveillance, but of its limits.