POLICY FORUM: PUBLIC HEALTH

Surveillance and Privacy

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Surveillance has been critical for epidemiological and population-based research into patterns of morbidity and mortality for a wide variety of diseases and conditions. However, the prospect of measures such as long-term monitoring, contact tracing, and quarantine has provoked alarm and concern about the potential for the unwarranted use of surveillance data.

Ethical issues are raised by public health surveillance regarding the extent to which name-based reporting violates trust and assumptions that are made about how medical information will be treated. For a brief period, there was discussion about whether emerging rules and regulations for human subjects research should apply to epidemiological studies, whether the principle of informed consent for the use of records was necessary, and if this requirement would render such inquiries virtually impossible. Yet that discussion had no impact on public health surveillance. Although epidemiological research has been the subject of ethical review, it is remarkable that public health surveillance has not been subject to similar oversight.

Name-based surveillance has been viewed as vital for public health, but has raised concerns. [1998, New York City, 8th Avenue near 34th Street.]

It was not until the late 19th century that systematic reporting of infectious diseases began. Surveillance was also undertaken to initiate quarantine, isolation, or vaccination (*1*) and provoked public and professional concern. Physicians, on occasion, challenged the authority of public health professionals to breach the sanctity of the doctor-patient relationship in the name of surveillance. In New York City, for example, physician outrage over mandatory tuberculosis (TB) reporting beginning in 1897 resulted in an essentially voluntary reporting system in which doctors withheld the names of their private patients and reported the names of their poor, dispensary cases.

Conflict also surrounded the reporting of sexually transmitted diseases (*3*). Although names were used in some locales, venereal disease reporting was often attenuated by compromises like those that emerged in the TB conflict. Nonetheless, this was not always so. In 1911, Western Australia adopted a compulsory name-based notification system for infectious diseases that included venereal diseases, seemingly without incident. Sweden followed suit in 1915, coupling name-based notification with compulsory detention, treatment, and prohibitions against marriage among the infected.

Eventually, name-based reporting was extended to a host of other conditions, typically without any sign of protest (*4*). But recognizing that resistance could undermine their efforts, public health officials began to develop the legal and organizational capacity for protecting the confidentiality of names.

Nonetheless, in the last part of the 20th century, a protracted and furious debate about surveillance would again surface. The U.S. controversy over HIV name reporting, beginning in 1985, was radically affected by the circumstances under which it emerged, e.g., the special fears surrounding the AIDS epidemic, a transformed conception of the rights of privacy, constitutional limits on state authority exercised for benevolent purposes, the development of a vigorous debate about medical ethics, and the emergence of patient advocacy as a potent social force. An increasing number of public health officials, who believed they could protect the confidentiality of name-based reports, found themselves pitted against AIDS activists and proponents of civil liberties who focused on the potential for discrimination and coercion if names were sent to public health registries.

When it became clear that some form of HIV infection reporting was necessary, the debate shifted to the question of whether relying on unique identifiers in lieu of names could meet surveillance requirements. The coalition opposed to name-based reporting insisted that a uniquely stigmatized disease demanded policies uniquely protective of privacy. Although some public health officials [such as those in Maryland] supported the use of unique identifiers, most remained skeptical. The U.S. Centers for Disease Control and Prevention (CDC) had, by the 1990s, become convinced that name-based reporting was most efficient and accurate. When, in 1999, it mandated that all states adopt some form of HIV surveillance, it only reluctantly acknowledged that, under stringent performance criteria, unique identifiers could serve public health adequately.

The emphasis on name reporting has been greater in the United States than in much of Europe. In February 1998, a meeting convened under the auspices of the European Centre for the Epidemiological Monitoring of AIDS concluded that, whereas HIV case reporting is essential, effective surveillance could be attained without the use of names (*6*).

Vaccine registries provide a counterpoint to HIV. In response to sporadic disease outbreaks, poor coverage in inner-city communities, increasingly complex vaccine schedules, family mobility, and poor provider and patient awareness of immunization coverage levels, the National Vaccine Advisory Committee (NVAC) recommended in 1999 creation of a nationwide network of state and community immunization registries. *Healthy People 2010* included a goal for surveillance, aiming for 95% registration of children up to age 5.

In the face of considerable anxiety, the federal initiative to register immunization coverage put a premium on community participation and cooperation. Immigrant communities feared that registry information would be used to deny medical coverage or to make reports to the Immigration and Naturalization Service. Parents who opted against vaccination were concerned that they

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would suffer harassment or discrimination. Finally, providers with low immunization rates worried that they would be "punished" in some fashion. As a result, a central concern of the NVAC was to protect patient confidentiality (*7*). The NVAC report recommended that, at a minimum, registries notify parents of the existence and content of the registry. Critically, it recommended that parents should be permitted to decide whether children would be included in registries.

Although cancer is historically a highly stigmatized disease and registration of cases in Western Europe has in recent years been the subject of strict regulation, cancer registries in the United States, which have been in existence for 50 years, provide the primary example of a surveillance regimen that has not produced ethical controversy. In 1973, the National Cancer Institute recognized that its strategy of ascertaining data on cancer through periodic surveys was inadequate. It established the Surveillance, Epidemiology, and End Results (SEER) program to take advantage of cancer data already being collected at population-based tumor registries. Nineteen years later, Congress enacted the Cancer Registries Amendment Act, which authorized the CDC to establish a national program in support of cancer registries. Despite the wide array of medical information linked by name and the duration of surveillance for each case from the first pathology report through death, most patients are unaware that cancer registries exist or that they represent cases within these registries. Supporters have argued for using names as the basis for linking records, in the name of surveillance accuracy (*8*). Those concerned with the needs and rights of breast cancer patients have supported cancer registries despite the commitment of the women's health movement to norms of privacy.

In 1997 it was estimated that as a result of occupational exposure, more than 800,000 individuals become sick and 60,000 die each year in the United States (*9*). Advocates for workers' health have urged that occupational diseases be made reportable by name to permit work site interventions and investigations. Ultimately, the National Institute for Occupational Safety and Health (NIOSH) developed the Sentinel Event Notification System for Occupational Risks (SENSOR) in 1987. SENSOR helps state programs to expand their reporting capacity and to develop standardized case definitions. A number of European nations have also developed special surveillance programs to monitor the health status of workers, for example, those exposed to asbestos. Although occupational disease reporting by name is uncommon in less developed nations, it does exist.

Birth defects registries emerged to meet environmental and teratogenic hazards to the fetus. Currently, the U.S. Birth Defects Monitoring Program, a multistate surveillance system based on hospital discharge reports, is the largest source of birth defects information in the nation (*10*). Although the architects of birth defects registries endorse the use of names to facilitate follow-up studies and the linkage of infant, maternal, and paternal records, they have embraced parental choice. In that way, they are like vaccine registries in that parents retain the right to decide whether or not their children will be subject to reporting. Birth defects and vaccine registries thus stand as a challenge to the proposition that only universal, name-based reporting without consent is an adequate basis for surveillance.

Conclusions

Five themes emerge that help to explain the circumstances under which surveillance is contested and those under which it is accepted without debate.

First, the extent to which surveillance might trigger public health interventions and the way such interventions have been viewed have been central. Fear that those reported would be the targets of coercion or discrimination has energized opposition to name-based reporting. A recent Institute of Medicine report provoked concern because it recommended screening and surveillance of immigrants from countries with a high incidence of TB and proposed that infected individuals be compelled to undergo prophylactic therapy or lose their immigrant status (*11*). In contrast, labor advocates have supported occupational disease reporting as a prelude to interventions that could protect workers from hazardous work site conditions. Similarly, cancer activists have viewed tumor registries as crucial to research that could lead to intervention or treatment.

A second theme is the extent to which proposals for reporting provoke resistance or alarm when they involve diseases carrying social stigma or touch those who view themselves as socially marginalized or vulnerable to social or economic injury. Affected individuals may find pledges that reported information will be protected from unwarranted disclosure hard to believe and, as a consequence, see themselves as endangered.

Third, special populations can elicit special protections. Thus, surveillance regimes involving children and reproduction have put a high premium on both confidentiality and informed consent.

Fourth, although constituencies have sometimes been highly alert to the potential imposition of a surveillance regime, that has not always been the case. In the case of tumor registries, the subjects of reporting remain largely unaware of ongoing reporting requirements. Without such awareness, the possibility of voicing privacy concerns remains out of reach.

Perhaps most important, changes in expectations regarding privacy have had a profound impact on the acceptability of name-based reporting systems and the willingness of policy-makers to consider alternatives. Registries that have developed most recently (particularly birth defects registries and vaccination registries) have been more sensitive to a culture of privacy than older ones, which find themselves challenged. For example, concerns have emerged about how commitments to privacy might eventually impede the extent to which tumor registries can serve as the basis for critical research.

Every U.S. state has statutes or regulations developed over the course of the 20th century that protect the confidentiality of names reported to disease registries. Nonetheless, existing state laws lack uniformity and make it difficult to define clearly the ways in which they will protect reported data from unwarranted disclosure. That the CDC supported the development of a model state public health privacy act to protect such information underscores the salience of this issue.

This is an opportune moment for analysis of ethical challenges posed by name-based reporting requirements. Such an effort would necessitate recognition that the protection of public health may require some limitations on privacy. The central ethical question posed by name-based reporting is whether an abrogation of medical privacy can be justified by public health benefits. Although medical privacy is a fundamental value, it is not an absolute.

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