Diabetes and Disease Surveillance

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In response to patient concerns about stigma and discrimination, Frieden argued that the privacy protections for the registry would be “stronger even than [those that] are in place for communicable disease reporting.” Confidentiality provisions, the department asserted, would explicitly prohibit data sharing “to make it more difficult for persons with diabetes to obtain or renew a driver’s license, health insurance, life insurance, etc.” (3). Indeed, health officials assured the public that data would not be released to other parties other than the patient’s physician.

The leadership of the ADA was quite receptive to surveillance, some viewing it as crucial for patients on the margins of the health care system—those who had no ongoing relationship with health practitioners. The organization, however, ultimately yielded to concerns of their membership and resolved that it could support A1C surveillance only if patients gave their informed consent.

Citizen objections to the surveillance proposal voiced at a public hearing in August 2005 were based on privacy and autonomy concerns. A medical privacy attorney, who explained that she also managed a chronic health condition, assured the public that invisible health registries across Canada and Europe (7, 8). Registries have been pilot tested in the United States (9).

Although the New York surveillance effort will cover the entire city, the disease management intervention will be piloted first in the South Bronx, a poor, largely African-American and Hispanic-American community with particularly high rates of diabetes. Thus, the measure is also groundbreaking in that public health is responding to what it has taken to be a moral risk. One diabetic expressed his “desire as a private citizen to keep my personal medical information private between my physician and myself and nobody else” (3).

The proposed incursion on privacy was unacceptable to such opponents because diabetes posed no communicable risk. One 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” (3). This 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” (10). One attorney representing health care groups concerned with medical privacy 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.” (3).

Absent the possibility of harm to others, the proposed system was characterized as an unwarranted intrusion into the domain of medicine. As did other ideologically libertarian organizations, the Association of American Physicians and Surgeons objected to lab-based A1C reporting as a “blatant invasion of patient privacy that will cause many patients to avoid testing and treatment.” It saw the plan as “replacing individualized medical care with population-based medicine for patients having one of our nation’s most significant chronic diseases” (11).

Diabetes registration could, argued opponents, only open the door to greater intrusions and drive people away from health care. One patient flatly rejected what he called a “Big Brother approach to diabetes management” (3). He shared the concerns of another citizen who asked, “Are you going to demand what I can and can’t eat?” (12). Only informed consent could mitigate such fears.

Against the claims of the individual were counterpoised those of the common good. That diabetes control, in particular, had 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 laboratory-based A1C reporting at the public hearing. A mantra of the testimony from the New York City Department of Health was an ongoing, systematic diabetes surveillance to ensure that patients receive appropriate treatment (14). Some members of the New York City Council, as part of its deliberations over the health department’s budget for fiscal year 2007, pressed for the health department to adopt an informed consent model (15). The American Civil Liberties Union is currently strategizing about how to weigh in on both the developments in diabetes and HIV surveillance. The time is thus right for an explicit discussion of the relations between public health surveillance, the claims of privacy, and the duty of public health to protect the interests of the most vulnerable.

Public health policy-makers must consider whether diabetes surveillance can really achieve all that it promises. But as important, and ultimately more vexing, are the underlying philosophical and political issues: We must distinguish paternalism in its most pejorative sense of overriding the judgment of individuals about their own health care from the commitment to providing for the most vulnerable in society who do not enjoy the benefit of a consistent, reliable relationship to a single provider or group of practitioners. Viewed from one vantage point, paternalism amounts to an unwarranted denial of privacy and choice; viewed from another, it holds the prospect of enhancing access to appropriate care, representing a commitment to social justice (16).

What distinguishes hard paternalism from its softer counterpart is the role of coercion. Despite the bristling rhetoric of those who would oppose diabetes surveillance—and, indeed, of city officials like Mayor Michael Bloomberg who have called for “the forceful application of law … as the principal instrument of our public health policy”—no one would be forced to undergo treatment or lifestyle change. If city officials hold true to their commitment to moving forward with such measures only when “democratically debated and approved,” surveillance can promote empowerment (17).

References and Notes
8. Registration in the Belgian Diabetes Registry; (www.bdronline.be).
10. Letter from P. M. Kazon, Alston & Bird, LLP, on behalf of the American Clinical Laboratory Association, 16 August 2005; available from (16).
12. Written communication in the Department of Public Health and Hygiene’s collection of public responses, from (18).
18. The Diabetes Prevention and Control Program, New York City Department of Health and Mental Hygiene, 2 Lafayette Street, 20th Floor, CN 46, New York, NY 10007, USA.
19. I thank R. Bayer, G. Carrino, and the two anonymous reviewers for their insightful comments and A. Alkon for her research assistance.

“Never has a government initiated ongoing, systematic diabetes surveillance for an entire population.”

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