Virtual Mentor

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POLICY FORUM

Mandatory Reporting of Noncommunicable Diseases: The Example of The New York City A1c Registry (NYCAR)

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Diabetes imposes a major public health burden on patients and the health care system. Today, 21 million Americans have diabetes, and an estimated 6 million of them are unaware of it [1]. One in three people born in the United States in 2000 will develop diabetes at some point in their lives [2]. In New York City, 500,000 people have diabetes, corresponding to an overall prevalence of 8 percent, ranging from 5.9 percent in Manhattan to 10.9 percent in the Bronx [3].

Complications of diabetes include heart disease, stroke, kidney failure, blindness, and lower extremity amputations. Nationwide, diabetes is the sixth leading cause of mortality [1]. Large-scale efficacy studies show that tight control of HbA1c (that is, the component of hemoglobin to which glucose is bound) produces a 20 to 50 percent reduction in microvascular complications [4]. Unfortunately, tight control (HbA1c < 7 percent) has been hard to achieve: 28 percent of New York City (NYC) patients with commercial insurance and 37 percent of those with Medicaid have “poor control” (A1c >9 percent) [5]. In fact, only 10 percent of patients even know what their A1c measurements are [6]. As more and more people are diagnosed, the cost of diabetes increases, both in dollars required to provide care and in hours devoted to care by health care professionals. The Centers for Disease Control and Prevention estimated in 2002 that the U.S. spent at least $132 billion annually on diabetes [1].

The New York City A1c Registry (NYCAR)

To help combat the rising incidence of type 2 diabetes, NYC’s Department of Health and Mental Hygiene (DOHMH) adopted a plan in December 2005 to monitor hemoglobin A1c. This new plan requires laboratories with electronic reporting capacity to upload data on hemoglobin A1c measurements to the NYC Department of Health [7]. Physicians and clinics that measure hemoglobin A1c in their offices are exempt. The DOHMH uses those results to create a hemoglobin A1c registry that contains: (1) A1c (date and result), (2) patient contact information and date of birth, and (3) clinician contact information [7]. In addition to the registry, which just maintains records, the DOHMH began a pilot project in the South Bronx in mid-2007 that follows the model of the Vermont Diabetes Information System [8]. In this model, clinicians will receive daily notifications of A1c levels >8.0 percent, quarterly updates of patients in their caseload stratified by A1c, and best practice
recommendations; patients will receive letters and educational materials when their A1c level exceeds 8.0 percent [7].

The purpose of the registry is twofold. First, the health department can use the aggregate A1c information to map patterns of glycemic control and, since the registry records patients’ dates of birth, the department will also be able to examine the emerging epidemic of type 2 diabetes in children [7]. Second, the pilot program will provide information to clinicians and their patients when patients’ A1c control is poor [7]. Physicians must participate in the registry, but patients are sent a letter that gives them an opportunity to opt out of the registry.

**Why Diabetes Reporting?**

While appealing from a public health perspective, NYCAR has sparked controversy. At the core of the debate is the tension between public health benefits and privacy of personal health information.

The contrast between diabetes and communicable infectious diseases is illustrative. There is broad consensus on reporting for communicable diseases: for example, all 50 states mandate reporting of tuberculosis, syphilis, and smallpox. Even the staunchest of privacy advocates have little argument with identifying and treating people who have tuberculosis to prevent transmission. Unlike tuberculosis, however, diabetes is not communicable, and some patients believe that the NYCAR is an unjustified invasion of privacy [6]. One patient went so far as to describe the program as the “Big Brother approach to diabetes management” [6].

Proponents of NYCAR say that it is certainly within public health’s purview to obtain information vital to tracking this emerging “epidemic”; the rapidly increasing occurrence of diabetes has been called an epidemic in the broad sense of that term. The policy makes provisions to help ensure patient privacy, such as allowing patients to opt out and promising that information obtained through the reporting system is accessible to no one but the patient, the clinician, and database supervisors. Moreover, NYCAR advocates can point to the precedent created by cancer registries. The New York State Cancer Registry contains data such as tumor location, cell type, stage, and some treatment information. This registry is not voluntary, requiring hospitals to report all new cancer diagnoses and patient names under penalty of law [9].

Granted, part of the rationale for the cancer registry is to try to discover whether there are environmental exposures that cause or increase the risk for cancer. But the registry requires reporting of any cancer, whether or not an environmental cause is suspected. In the past, cancer registries have been relatively noncontroversial [10]. Recently, however, the Veterans Administration (VA), which is not subject to the same reporting obligations as other hospitals, announced that they will no longer report cancer data to state registries due to privacy concerns, even though they had been reporting since 1974 [11]. Concerned about patient privacy, the VA is requiring all states to sign a directive mandating that patient information be encoded so that
Unauthorized people cannot gain access to it. Authorized researchers must either (1) get permission from the VA’s Under Secretary of Health to gain access to the data, or (2) find a VA researcher with whom to collaborate and get permission from that researcher’s VA hospital board of ethics [11].

NYCAR supporters acknowledge the risk of invasion of privacy that the registry poses. Historically, privacy concerns are not uncommon when health departments require reporting of patient information. When tuberculosis reporting was introduced in New York in 1897, physicians resisted on the basis that patient privacy might be violated [11]. NYCAR supporters point out that the confidentiality controls for A1c data are more stringent than those for communicable diseases and that the growing crisis calls for bold action. Given the gravity of the diabetes-related public health threat, many believe that monitoring A1c levels is justified.

Implications of the Registry
Whether or not one thinks mandatory reporting of A1c measurements is an appropriate use of public health authority, the important question is: will the policy make a significant impact on this growing health problem? Immediate A1c feedback at patient points of care seems to help improve control [12, 13]. Research has also shown that feedback and reminders to clinicians and increased information to patients help improve diabetes control [14, 15]. For example, Intermountain Health Care in Salt Lake City developed a Diabetes Care Management System that included the creation of a registry of A1c, cholesterol, and urine microalbumin results, feedback to providers about how their patients’ lab values compared to others in the region, educational materials to patients and providers, and alerts to providers when testing was overdue. Over 4 years, the average A1c decreased from 8.1 percent to 7.3 percent [14]. Perhaps the registry will provide the impetus for managing individual patients differently and for overcoming clinical and systemic hurdles to making therapy changes when they are indicated.

And perhaps poor diabetes control is more communicable than originally thought. A recent study shows that obesity may be contagious to three degrees of separation [16]; that is, it can be “transmitted” through social interactions among friends and even friends of friends. If so, then obesity’s sequelae, including diabetes, can also be transmitted. Population-wide dispersion of A1c data into multiple social networks might magnify the benefits of patient and provider feedback beyond what has been detected in clinic-based studies.

NYCAR is not a solution to the diabetes epidemic: it is purely informational; it does not facilitate treatment to achieve control; and it does not identify individuals with undiagnosed diabetes or prediabetes. What NYCAR does is establish a novel framework for public health monitoring and decision making that has already begun to raise awareness of the diabetes epidemic. Epidemics require bold public health action. This is a worthwhile experiment for the nation to watch, and if successful, to emulate.
References


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