

# Virtual Mentor

American Medical Association Journal of Ethics  
December 2007, Volume 9, Number 12: 827-831.

## POLICY FORUM

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

Clarissa G. Barnes, Frederick L. Brancati, MD, MHS, and Tiffany L. Gary, PhD, MHS

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

1. Centers for Disease Control and Prevention. *National Diabetes Fact Sheet 2005*. [http://www.cdc.gov/diabetes/pubs/pdf/ndfs\\_2005.pdf](http://www.cdc.gov/diabetes/pubs/pdf/ndfs_2005.pdf). Accessed September 30, 2007.
2. Narayan KM, Boyle JP, Thompson TJ, Sorenson SW, Williamson DF. Lifetime risk for diabetes mellitus in the United States. *JAMA*. 2003;290(14):1884-1890.
3. New York State Department of Health Diabetes Prevention and Control Program. *The State of Diabetes in New York State: A Surveillance Report-2007*. [http://www.health.state.ny.us/statistics/diseases/conditions/diabetes/surveillance/docs/report\\_1997-2004.pdf](http://www.health.state.ny.us/statistics/diseases/conditions/diabetes/surveillance/docs/report_1997-2004.pdf). Accessed September 30, 2007.
4. Gaede P, Videl P, Larsen N, Jensen GV, Parving HH, Pedersen O. Multifactorial intervention and cardiovascular disease in patients with type 2 Diabetes. *N Engl J Med*. 2003;348(5):383-393.
5. New York State Department of Health. *Managed Care Plan Performance-2006*. [http://www.nyhealth.gov/health\\_care/managed\\_care/qarrfull/qarr\\_2006/qarr2006.pdf](http://www.nyhealth.gov/health_care/managed_care/qarrfull/qarr_2006/qarr2006.pdf). Accessed September 20, 2007.
6. *Public Hearing on Intention to Amend Article 13 of the New York City Health Code*. (August 16, 2005).
7. Silver LD, Berger DK. *Improving Diabetes Care for All New Yorkers*. New York, NY: City Department of Health; 2005. <http://www.nyc.gov/html/doh/downloads/pdf/diabetes/diabetes-presentation-a1c-registry.pdf>. Accessed September 30, 2007.
8. Maclean CD, Littenberg B, Gagnon M, Reardon M, Turner PD, Jordan C. The Vermont Diabetes Information System (VDIS): study design and subject recruitment for a cluster randomized trial of a decision support system in a regional sample of primary care practices. *Clin Trials*. 2004;1(6):532-544.
9. New York State Department of Health. *About the New York Cancer Registry*. Revised February 2007. <http://www.health.state.ny.us/statistics/cancer/registry/about.htm>. Accessed September 20, 2007.
10. Bayer R, Fairchild AL. Public health: surveillance and privacy. *Science*. 2000;290(5498):1898-1899.
11. Kolata G. States and V.A. at odds on cancer data. *New York Times*. October 10, 2007. [http://www.nytimes.com/2007/10/10/health/10cancer.html?pagewanted=2&\\_r=1&ref=health](http://www.nytimes.com/2007/10/10/health/10cancer.html?pagewanted=2&_r=1&ref=health). Accessed October 13, 2007.
12. Cagliero E, Levina EV, Nathan DM. Immediate feedback of HbA1c levels improves glycemic control in type 1 and insulin-treated type 2 diabetic patients. *Diabetes Care*. 1999;22(11):1785-1789.
13. Miller CD, Barnes CS, Phillips LS, et al. Rapid A1c availability improves clinical decision-making in an urban primary care clinic. *Diabetes Care*. 2003;26(4):1158-1163.

14. Larsen DL, Cannon W, Towner S. Longitudinal assessment of a diabetes care management system in an integrated health network. *J Manag Care Pharm.* 2003;9(6):552-558.
15. Philips LS, Ziemer DC, Doyle JP, et al. An endocrinologist-supported intervention aimed at providers improves diabetes management in a primary care site: improving primary care of African Americans with diabetes (IPCAAD) 7. *Diabetes Care.* 2005;28(10):2352-2360.
16. Christakis NA, Fowler NH. The spread of obesity in a large social network over 32 years. *N Engl J Med.* 2007;357(4):370-379.

Clarissa Barnes is a fourth-year medical student at the Johns Hopkins University School of Medicine in Baltimore. She intends to pursue residency training in internal medicine. Her research interest focuses on public health policy, especially as it relates to chronic and infectious disease epidemics.

Frederick Brancati, MD, MHS, is a professor of medicine and epidemiology and director of the General Internal Medicine Division at Johns Hopkins University School of Medicine in Baltimore. His research focuses on the epidemiology and prevention of type 2 diabetes and related conditions.

Tiffany L. Gary, PhD, MHS, is an assistant professor in the Department of Epidemiology at the Johns Hopkins University Bloomberg School of Public Health in Baltimore. She also holds a joint appointment in the General Internal Medicine Division at the Johns Hopkins University School of Medicine and is a core faculty member in the Welch Center for Prevention, Epidemiology, and Clinical Research and the Center for Health Disparities Solutions. Dr. Gary's current research program includes social epidemiology, advanced statistical methods, and the content areas of diabetes and obesity.

#### **Related in VM**

[Privacy and Public Health Surveillance: The Enduring Tension](#), December 2007  
[Surveillance of Infectious Diseases Is Information in Action](#), April 2006

*The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.*

Copyright 2007 American Medical Association. All rights reserved.